

Staying active despite pain:

Investigating feedback mechanisms
to support physical activity in people
with chronic musculoskeletal pain

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Declaration

I, Aneesha Singh, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Abstract

Chronic (persistent) pain (CP) affects 1 in 10 adults; clinical resources are insufficient, and anxiety about activity restricts lives. Physical activity is important for improving function and quality of life in people with chronic pain, but psychological factors such as fear of increased pain and damage due to activity, lack of confidence or support, make it difficult to build and maintain physical activity towards long-term goals. There is insufficient research to guide the design of interactive technology to support people with CP in self-managing physical activity. This thesis aims to bridge this gap through five contributions: first, a detailed analysis from a plethora of qualitative studies with people with CP and physiotherapists was done to identify factors to be incorporated into technology to promote physical activity despite pain. Second, we rethink the role of technology in improving uptake of physical activity in people with CP by proposing a novel sonification framework (*Go-with-the-flow*) that addresses psychological and physical needs raised by our studies; through an iterative approach, we designed a wearable device to implement and evaluate the framework. In control studies conducted to evaluate the sonification strategies, people with CP reported increased performance, motivation, awareness of movement, and relaxation with sound feedback. A focus group, and a survey of CP patients conducted at the end of a hospital pain management session provided an in-depth understanding of how different aspects of the framework and device facilitate self-directed rehabilitation. Third, we understand the role of sensing technology and real-time feedback in supporting functional activity, using the *Go-with-the-flow* framework and wearable device; we conducted evaluations including contextual interviews, diary studies and a 7-14 days study of self-directed home-based use of the device by people with CP. Fourth, building on the understanding from all our studies and literature from other conditions where physical rehabilitation is critical, we propose a framework for designing technology for physical rehabilitation (RaFT). Fifth, we reflect on our studies with people with CP and physiotherapists and provide practical insights for HCI research in sensitive settings.

~To amma, with love~

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Publications and Awards

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Awards

- People's Choice Award at the Research Spotlight, London Hopper Colloquium, 2015
- Most innovative student-driven digital award, mHealth Habitat - Runner up, 2015
- Finalist at the Social Innovators Challenge run by UCL, Numbers4Good and HealthBox, 2015.
- *Go with the flow* app was awarded 2nd prize at UCL Festival of Digital Health Gamification and Self-tracking event, Festival of Digital Health at UCL, 2014.

Glossary

Abbreviation	Term
CP	Chronic pain
CBT	Cognitive Behavioural Therapy
PMP	Pain Management Programme
CCBT	Computerised Cognitive Behavioural Therapy
VR	Virtual reality
BCW	Behaviour Change Wheel
TPB	Theory of Planned Behaviour
TRA	Theory of Reasoned Action
SCT	Social Cognitive Theory
SDT	Self Determination Theory
TIB	Theory of Interpersonal Behaviour
RPT	Relapse Prevention Theory
HBM	Health Belief Model
TTM	Transtheoretical Model
GST	Goal Setting Theory
NHNN	National Hospital of Neurology and Neurosurgery
COPE	Changing the Outcomes of Pain Experiences

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Chapter 1 Introduction

Chronic (persistent) pain (CP) is a restricting condition with a low rate of spontaneous recovery. It is a leading cause of disability in the United Kingdom and one of the most common medical problems people face. Statistics put the number of people living with CP in the UK at 7.8 million (Donaldson 2009) and of these 1.6 million adults have chronic back pain (Donaldson 2009). CP has a significant impact on quality of life; statistics suggest that between 50 - 65% of people with CP are unable to carry on normal lives (Donaldson 2009). Even the most potent analgesics are able to provide significant pain relief to only 30% of people with CP and even within the studies reporting significant pain reduction, commensurate increases in physical or emotional function do not necessarily occur (Turk 2002).

There is now good evidence that staying active can improve function and pain for people with CP (Koes et al. 2006; Hayden & van Tulder 2005). Being active protects against weakening and stiffness, inhibits the neurophysiological mechanisms underlying the spread of pain, increases confidence in physical capacity and underpins achieving valued goals (Gatchel et al. 2007). However, for people with CP, maintaining physical activity despite ongoing pain is a challenge. When support is available (e.g., from physiotherapists during pain management programmes), people with CP manage to increase their physical and psychological capabilities (Turk & Okifuji 2002). However, clinical services cannot meet continued demand (Donaldson 2009) and without support gains diminish.

Technology offers a way to support self-managed physical activity, but to achieve behaviour change, factors that undermine adherence need to be examined. Some of these psychological factors include fear that the pain indicates physical damage (Crombez et al. 2012), anxiety about worsening of pain through physical activity (Nagarajan & Nair 2010; Huijnen et al. 2010; Leeuw et al. 2007), a catastrophic way of interpreting pain-related information and experience (Schütze et al. 2010), depression (Geisser et al. 1994) or vigilance to pain (Keogh et al. 2003). Other factors that may stop people with CP from activity or exercising include a lack of time as physical and emotional resources are limited, low motivation and boredom (Nigg et al. 2008; Rejeski & Mihalko 2001).

An interdisciplinary approach to treatment is useful in the rehabilitation of people with CP, primarily involving psychology and physiotherapy (Kerns et al. 2011). The aim of the multidisciplinary approach is for the person with CP to accept and learn to self-manage his/her condition (rather than reduce pain) and, in doing so, achieve greater independence, more

satisfaction with activities and social relationships, and a better overall quality of life (Harding & Williams 1995; Smith & Torrance 2011; Williams et al. 2012). To do this, healthcare professionals on pain management programmes (PMPs) address negative psychological factors, such as fear of further damage and pain mentioned earlier, using evidence based approaches such as cognitive behaviour therapy (CBT). While inpatient and outpatient PMPs are successful in improving physical function and reducing distress associated with pain during the programme (Williams et al. 2012), there is much less evidence that treatment gains are maintained in the longer term (Turk 2002).

Technology can help people with CP to maintain and build on these treatment gains by providing support and tools for self-management in the long term. However, existing technology in this area is in very early stages of development (Keogh et al. 2010). Information resources are available to CP patients on computers (Hochlehnert et al. 2006) and online (Polomano et al. 2007) and aspects of CP management have been delivered on the Internet or by telephone (Macea et al. 2010). Although this is a significant step forward in making support accessible to patients, it still needs ongoing support from the physiotherapist or other clinician to work especially in addressing the psychological barriers associated with CP (Rosser et al. 2011). Electronic diaries are available as a means for people with CP to record (Burton et al. 2007) and monitor (Keogh et al. 2010) their symptoms but monitoring by itself is not an effective way to change behaviour when psychological support available from clinicians/physiotherapists during physical activity ends (e.g., reassurance and tips during performance of movement, building confidence, knowing when to progress).

A few attempts to build technology to directly support physical rehabilitation in CP have been made but the emphasis is mainly on physical progress in the presence of a physiotherapist who still provides psychological support (e.g., Schönauer et al. 2011). These technologies have been modelled on technological advances in conditions other than CP, such as stroke and on the model of clinically-situated physiotherapy. Unfortunately, this model cannot work for CP rehabilitation, as support from healthcare providers in CP is limited. In CP, people must self-direct their rehabilitation in the long-term and pain is not something that has to be endured only during exercise but is also constantly present and perceived as a threat that may lead to setbacks and (re)injury. There is also a lack of frameworks to guide the design of technologies aimed at unsupervised physical rehabilitation in general. Designers translate traditional clinical models of rehabilitation where the physiotherapist is present into technology. The same can be said for game-based rehabilitation technologies designed for regaining physical capability as they are based on the model of acute pain (e.g., post-operation) rather than CP, or are designed to recover fine-grained motor capability (e.g., in stroke).

Technologies designed for fitness in the general healthy population have tackled the motivational aspects of engaging with physical activity through the use of gamification and rewards (e.g., Consolvo et al. 2009; Albaina et al. 2009). Unfortunately, these technologies are inadequate for CP because they do not address the emotional barriers faced by people with CP. While these technologies do address the need for feedback and monitoring that encourage self-efficacy, this is only effective when the individual targeted feels capable of the behaviour. This leads to the question of how we can design physical activity technology for self-directed rehabilitation for conditions such as CP when the psychological barriers go far beyond frustration and lack of motivation.

Our aim¹ is to incrementally build a deeper understanding of CP and CP rehabilitation and use this understanding to inform technology designed to support people with CP to remain physically active.

1.1 Research questions, approaches and contributions

According to the literature briefly outlined above (and discussed in more detail in the next few chapters), people with CP find it difficult to maintain a programme of physical activity due to physical and psychological factors associated with pain. Therefore, this thesis aims to answer the following research question:

RQ: How can interactive technology support people with CP in overcoming psychological barriers during self-directed physical rehabilitation?

This leads to three further sub-questions that are presented here along with the approach adopted to address them and the associated contribution. A summary of the research questions, studies and outcomes are provided in Figure 1-1.

¹ This thesis is part of the Emo&Pain project and was funded by it (www.emo-pain.ac.uk). The aim of the Emo&Pain project is to design and develop an intelligent system that will enable ubiquitous monitoring and assessment of patients' pain-related mood and movements inside (and in the longer term, outside) the clinical environment. Further the project aims to provide appropriate feedback and prompts to the patient based on his/her behaviour measured during self-directed physical therapy sessions.

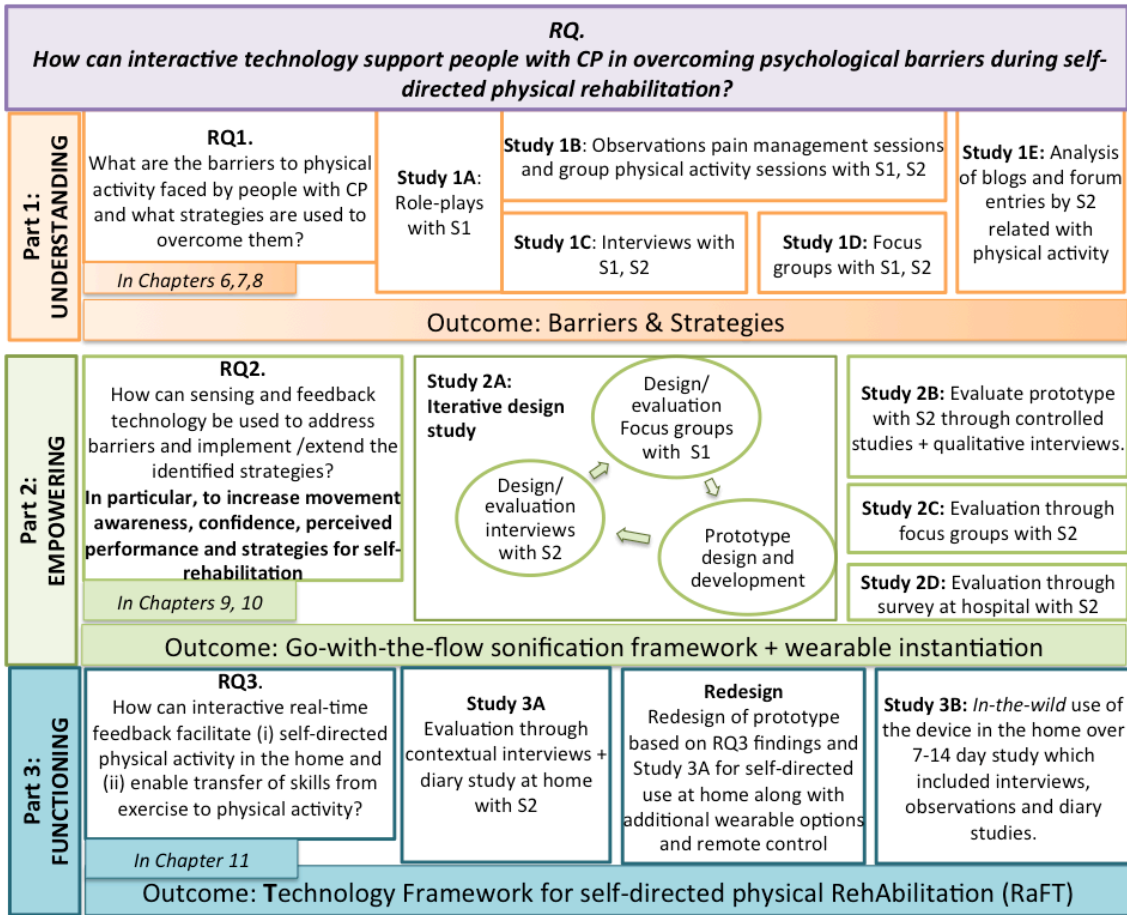


Figure 1-1: Research questions, studies and outcomes. S1 refers to physiotherapists; S2 refers to people with CP. These were the two primary stakeholders for this thesis.

RQ1. What are the barriers to physical activity faced by people with chronic pain and what strategies are used to overcome them?

Through a set of incremental qualitative studies, we investigated in depth the barriers to physical activity encountered by people with CP and the strategies that they use to overcome them. We approached this question from two perspectives: (i) the practical challenges faced by people with CP in maintaining physical activity, and strategies they use to build activity, and (ii) how physiotherapists, specialised in pain rehabilitation, support and motivate people with CP to build physical activity. These complementary perspectives enabled us to identify technology opportunities. Whereas people with CP can provide an account of their needs, of barriers and strategies used to meet them, they lack a formulation of their rehabilitation needs; physiotherapists with an understanding of CP can judge what type of activity is beneficial and achievable and link it to valued goals.

An initial appreciation of barriers to activity that people with CP encounter was obtained

through simulated role-plays with physiotherapists. This understanding was broadened through interviews with people with CP and physiotherapists and further clarified and discussed through focus groups with people with CP and physiotherapists. Analysing publicly available blogs and forum entries gave us a personal account of barriers and strategies in a naturalistic environment not moderated by us. Strategies applied to overcome barriers were observed in practice through observations of group pain management sessions directed by physiotherapists: within these sessions we observed how physiotherapists supported exercise and activity and also how people with CP engaged in it. This was followed by analysis of cued interviews of the videos with physiotherapists to understand their strategies to motivate people and address psychological barriers to activity in people with CP. The studies built on each other and what emerged was a richer picture of the barriers and strategies for physical activity from the perspective of people with CP and physiotherapists who specialise in CP management. This led to the next question of how technology can be used to empower the strategies that emerged.

First Contribution (Chapters 6-8): The studies built on each other and what emerged was a rich picture of the barriers and strategies for physical activity from the perspective of people with CP and physiotherapists who specialise in CP management. This led to the next question of how technology can be used to empower the strategies that emerged.

RQ2. How can sensing and feedback technology be used to implement, extend and empower the strategies identified for overcoming psychological barriers?

Using the understanding gained from the studies conducted in the previous research question, we investigated how sensing and feedback technology could provide the necessary psychological and physical support for facilitating physical activity in people with CP in the absence of a physiotherapist. Our focus was on providing real-time support in the absence of a physiotherapist using body tracking technology and related physiological feedback. Our approach to address this question was to address psychological barriers identified through the previous studies and the literature rather than simply tracking movement and providing feedback to correct it or to post-reflect on it. Tracking of body movement has been used as a means for providing real-time support in the literature but there is a gap in addressing the psychological needs at run-time, as discussed in Chapter 4. We proposed the use of movement sonification (the real-time mapping of data into sound) as a way to implement the strategies that emerged from our studies to address the psychological needs of people with CP. The use of sonification to address psychological barriers has not been explored in the literature where it has

mainly been used as a motivation tool and a means to provide information about correctness of movement during sport and rehabilitation.

Second contribution (Chapter 9-10): We used an iterative design approach, where technology is used as a research tool, to propose a sonification framework that implements, extends and empowers the strategies identified in the first study. The aim of the framework is to guide the design of sonifications that address the psychological needs of people with CP while engaging in physical activity. Control studies were used to evaluate the framework and the technology in the context of exercise and in the context of transferring from exercise to function. Further qualitative studies, including a survey at the hospital, led to a better understanding of how the proposed framework was helpful.

RQ3. How can interactive real-time feedback facilitate (i) self-directed physical activity in the home, and (ii) enable transfer of gains from exercise to everyday functional activity?

Finally, we investigated how technology can facilitate physical activity beyond exercise using the designed technology in their home through situated *in-the-wild* studies. From the first studies, it emerged that people with CP faced challenges in transferring gains from exercise to function, so we explored this in the controlled evaluation and subsequently when people used the device in the home for exercise and function. We used the contextual inquiry method to reinforce the importance of context through an initial exploratory study of the technology. A 7-14 days study was conducted with the device being used by people in the home and data was captured through a diary, periodic interviews and sensor logs.

Third Contribution (Chapter 11): The results confirmed the efficacy of the device and the framework. They also highlighted how such types of device can help transfer psychological and physical gains from exercise to functional activity and also from functional activity to exercise hence making exercise more effective. Finally, the findings highlighted the opportunity that such technology offers to develop strategies to perform functional (physical) activity (that cannot be avoided) whose demand is beyond the current psychological capabilities.

Finally, using the findings from all the studies and literature in other conditions, we make two more contributions:

Fourth Contribution (Chapter 12): based on our studies with people with CP and physiotherapists we propose an initial framework to guide the design of rehabilitation technology for physical activity support (RaFT) where psychological barriers are critical.

Fifth Contribution (Chapter 13): we present reflections from our studies to provide insights into the challenges faced by HCI researchers when working in such sensitive contexts without clinical or psychological training. Building on these reflections we propose a set of initial practical recommendations to run HCI studies such as ours.

1.2 Scope

This thesis focuses on developing technology for real-time physical activity support in people with CP, specifically in people with musculoskeletal lower back CP. Our focus throughout this thesis is on supporting self-directed physical activity in real-time, which is an aspect of CP self-management that has been overlooked, rather than full CP self-management. Also, the technology developed does not claim to cure pain but to support people to address the psychological barriers to remain active despite pain

1.3 Structure of this thesis

This thesis is structured as follows:

Background and literature review

These chapters provide a background to key factors driving this research (Chapters 2, 3 and 4). We first present, in Chapter 2, an overview of the psychosocial factors implicated in CP that can interfere with physical activity in people with CP and current therapies used in CP management. In Chapter 3, we present relevant theories and models of behaviour change around physical activity to investigate if these can inform the design of technology for CP. In Chapter 4, we present a review of existing technology for physical activity behaviour change and/ or rehabilitation in people with CP, chronic illness and the generally healthy population.

Thesis methodology

In Chapter 5, we present the methodologies adopted throughout this thesis since it has a combination of qualitative and quantitative studies. After presenting an overview of the methodologies used for all the studies in this thesis, we provide further details of all the analysis methods used in the qualitative studies. We present the specific quantitative and design methods in relevant chapters, as they are not pervasive in all research questions.

Studies for RQ1, RQ2 and RQ3.

From here, the thesis is split into three parts based on the research questions presented in the previous section.

Part 1 - Understanding: In Part 1 (Chapters 6-8), we present the qualitative studies conducted with people with CP and physiotherapists to investigate barriers to physical activity in people with CP and strategies to overcome these barriers. In Chapter 6, we discuss each of the user study methods in detail for all the studies conducted including interviews, focus groups, observations and analysis of blogs and forum entries. In Chapter 7, we present findings from role-plays with physiotherapists, observation studies conducted at sessions run by pain management physiotherapists and attended by people with CP, interviews conducted with people with CP and physiotherapists, focus group studies and the analysis of online blogs and forum entries written by people with CP.

Part 2 – Empowering: In this second part (Chapter 9, 10), we present the design and development of a sonification framework, “*Go-with-the-flow*” to support physical activity in people with CP. We also present the process to create and evaluate a technology prototype designed as a research mechanism to investigate how sonification of people’s movement and respiration can be used to overcome psychological barriers and increase self-efficacy during physical activity in people with CP. The sonification framework is presented and evaluated through a control study and focus group study.

Part 3 – Functioning: Here (Chapter 11), we investigate the use of the sonification framework and self-calibration for situated use in the home beyond exercise for functional activity. We evaluate situated self-directed use of the “*Go-with-the-flow*” framework and device through two qualitative home studies.

Finally, in Chapter 12, we propose a framework for designing technology for self-directed physical rehabilitation (RaFT) based on all the findings from parts 1, 2 and 3 of the thesis,

Reflections and insights into conducting studies

In Chapter 10, we discuss reflections from the studies based on our encounters with people with CP and discuss the impact on the participants and the researcher. We also present practical insights into how we addressed some of the issues that emerged.

Conclusions

Finally, in Chapter 11, we conclude this thesis by summarising our research questions, studies and findings and reiterating our contributions. We also reinforce the broader implications of this research (beyond CP) and the potential for future research.

Chapter 2 Background: Chronic Pain

Existing work around chronic pain (CP), doing physical activity despite CP and using technology to support CP is currently scattered among a variety of domains; these include psychology (for information on the CP condition and psychological and social factors that affect it), physiotherapy (for physical activity around CP), behaviour change, human-computer interaction, persuasive healthcare and rehabilitation technology. The focus of this chapter is on the literature from the domains of psychology and physiotherapy, which will help to frame the issues faced by people with CP when attempting a programme of physical activity. Further, this chapter will discuss evidence based psychological interventions used to overcome barriers to physical activity faced by people with chronic pain and identify gaps in applying them to technological solutions. The behaviour change literature and technology for rehabilitation and physical activity that is currently available are reviewed in the next two chapters.

This chapter begins with a brief introduction to CP, the psychosocial aspects of the CP condition and models to describe these. The maintenance of physical activity in the long term despite ongoing pain is a challenge and the numbers of people needing help far outstrips clinical resources (Donaldson 2009). Technology can be a practical way forward for motivating increases in self-managed physical activity, but for any behaviour change technology to be effective, the reasons that prevent people with CP from exercising and those that motivate them to do more need to be examined. For this reason, next we examine the literature for psychosocial factors that affect people with CP and discuss models that explain how these factors affect them. We then discuss if existing traditional psychosocial interventions that are used in pain management can be used in technological interventions.

2.1 Introduction to CP

Pain is a multidimensional experience. The International Association for the Study of Pain (IASP) defines pain as “an unpleasant *sensory* and *emotional* experience associated with actual or potential tissue damage or described in terms of such damage” (Pain 1979). This definition emphasises that pain is a complex phenomenon beyond *nociception* – rather it brings psychological and emotional components of pain into the forefront. It also clearly specifies that pain cannot be defined by the presence of physical pathology or damage, nor denied based on its absence. Pain is fundamentally threatening; it warns and encourages avoidance and promotes escape behaviours, focuses attention to itself and signals danger to others. Additionally, pain can be accompanied by altered body movements and facial expressions (Sullivan 2008).

A distinction is made between acute pain and chronic pain. Chronic (persistent) pain (CP) is defined by time-scale as pain that persists past the phase of healing after injury (usually 3 months), after disease resolution, or occurs with no finding of lesion or pathology (Pain 1979). This is different from acute pain, which disappears as injury heals (Loeser & Melzack 1999) or which is related directly to the progress of disease, as in many cancers.

CP's impact on the individual is greater than just the pain itself: it can affect work, personal and social relationships, everyday functioning, and leisure activities of the person with CP. Inescapable pain can lead to depression, anxiety and social isolation. Biomedical models of pain are not sufficient to explain the physical, cognitive, emotional and social aspects of the CP experience and the impact that CP has on the quality of life of people (Gatchel et al. 2007).

2.2 The impact of CP and the biopsychosocial model

CP is not just physical, but includes emotions, cognition and behaviour (Gatchel et al. 2007). To describe this multidimensional nature of pain, the *biopsychosocial* theoretical model (Gatchel et al. 2007; Keefe & France 1999) presents an integrated understanding of pain. The biopsychosocial model builds on the *gate control theory* of pain, which describes pain as a phenomenon in which ascending sensory inputs from the peripheral nerves are continuously and rapidly modulated by other afferent input and by downward messages from the brain including the limbic system where important affect processing takes place (Melzack 2005; Loeser & Melzack 1999). A person's mood, cognitive function and memories play a part in amplifying or inhibiting the pain signal. However, in people with CP, disturbed pain modulatory circuits can cause abnormal amplification of the pain signal (Woolf 2010). Constant stimulation of the pain pathways by peripheral stimuli and/or changes in sensitivity of synapses in the pathways processing pain cause plastic changes in the morphology and neurochemistry of parts of the brain, over timescales from seconds to months and years (Shyu & Vogt 2009). Many of these processes have been discovered through animal studies (Cao et al. 2009) and through functional imaging in humans. A sensitised pain system can involve (i) hypersensitivity to normal pain stimuli, (ii) pain from normally non-painful stimuli, (iii) spontaneous generation of pain. These in turn cause further physical effects, such as muscle tension and guarding, through to relative immobility and disinclination to move, and emotional effects like anxiety, depressed mood, and frustration (Arnold et al. 2011; Mounce et al. 2010).

The *biopsychosocial* model (Gatchel et al. 2007; Keefe & France 1999) presents an integrated understanding of pain in which (i) the physical, psychological and social factors interact in the experience of pain and (ii) a dynamic exchange between these factors causes biological, psychological and social changes in the individual that affect future responses to pain. The

model attempts to integrate the biological, psychological and social factors implicated in pain because none of those alone explains pain (Gatchel et al. 2007). In fact, an individual's appraisal of his or her pain or beliefs about the meaning of pain affect the way s/he copes with it (Turk & Okifuji 2002). Negative beliefs about what pain symptoms mean and ability to control pain can negatively affect psychological and physical functioning, coping efforts and response to treatment (Turk 2002). For example, fear that a particular movement may cause further injury can cause the person to avoid that movement leading to increased pain and disability (Vlaeyen & Linton 2000). Ironically, physical activity can contribute to increased function and better quality of life (van Middelkoop et al. 2011; Koes et al. 2006; Chou et al. 2007; Indahl 2004). Addressing pain beliefs and psychological factors is, therefore, crucial in supporting physical activity in the person with CP.

2.3 Psychosocial barriers to physical activity adherence

The focus of this thesis is on increasing and maintaining physical activity in people with CP which is influenced by psychological and social aspects (Keefe et al. 2004; McCracken & Thompson 2011; Eccleston 2001). Pain as an alarm system imposes new behavioural priorities and encourages people to learn more about it and how to avoid it. While pain is not a sign of damage in CP, yet asking people to ignore such a fundamental signal of danger and continuing with physical activity can appear counterintuitive to them.

Psychological aspects of pain can be considered in terms of cognitive content, cognitive process and emotion (Daniel & Williams 2010). Cognitive content describes unhelpful beliefs about what pain means to the individual; people usually interpret pain as threatening and respond by withdrawal, escape from and avoidance of the situation. This frequently leads to reduction in the range and extent of activity, which can affect work, family, social life and self-care. Cognitive processing of these beliefs can lead to cautious behaviour in people with CP with the overestimation of threat and underestimation of the individual's capacity to cope which can again lead to reduced activity, a corresponding reduction in valued activities and social isolation. Emotional difficulties associated with pain are most usually described in terms of anxiety, about the meaning of pain and its implications; depression, often related to losses of valued activities and plans for the future; and frustration both about day to day difficulties and about the lack of medical solutions.

The rest of this section presents the psychological factors and associated theory which are important in the context of this thesis to (i) reduce the barriers to physical activity faced by people with CP, (ii) relate the psychological factors to associated behaviour and hence provide a link to existing behaviour change interventions that are most suitable for people with CP. The

latter is important because an understanding of the psychological factors and theories can help to make the technological solutions testable against current studies and interventions in psychology.

2.3.1 Fear, anxiety and pain catastrophising

The association of pain with threat can cause *fear*, *anxiety* and *catastrophising* about the meaning of pain (Leeuw et al. 2007; Vlaeyen & Linton 2000; Pincus et al. 2010); these factors can exert a significant impact on the level of function and pain tolerance of individuals with CP.

Fear is due to an imminent threat and predicts flight responses (escape). *Anxiety*, on the other hand, is an anticipation of threat and causes preventative behaviours like avoidance (Leeuw et al. 2007). In the literature on pain both terms are often used interchangeably because a distinction between the two is difficult to draw in CP where the threat is always present (Leeuw et al. 2007). Pain *catastrophising* is the cognitive element of fear conceptualised as “*an exaggerated negative mental set brought to bear during actual or anticipated pain experience*” (Sullivan et al. 2001) (e.g. “my spine is crumbling so I should strain it as little as possible”).

The fear-avoidance model (Leeuw et al. 2007; Vlaeyen & Linton 2000) suggests that people with CP avoid certain movements that exacerbate their pain and/or can cause (re)injury. The model, shown in Figure 2-1, explains that after injury, if the experience is appraised as non-threatening, the person steadily returns towards a more normal lifestyle. However, if the pain is interpreted as indicative of serious injury, the individual experiences fear/ anxiety and avoids activities believed to be risky or perceived to exacerbate pain (Gatchel et al. 2007). Furthermore, avoidance of activities, previously experienced as painful, is reinforced by a reduction in pain in the short term (McCracken et al. 1993), but in the long term leads to decreased activity and further distress and disability.

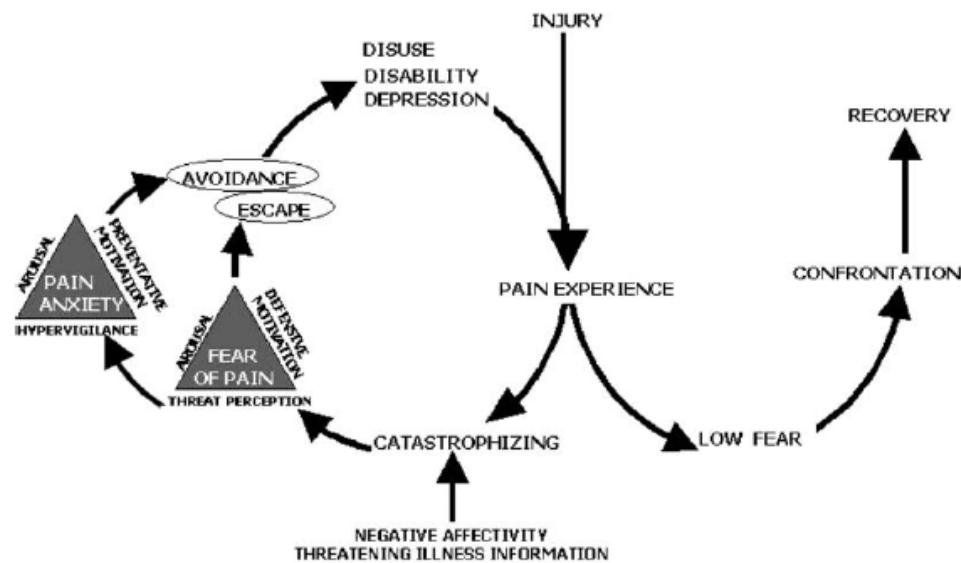


Figure 2-1. The fear--anxiety-avoidance model of CP (Leeuw et al. 2007). Reproduced with permission.

The fear avoidance model provides a useful, understanding of the development of chronicity after an acute episode but has been criticised for oversimplifying factors that drive avoidance behaviour. A major criticism of the fear-avoidance model is that it implies that if people return to normal activity after injury they will not develop CP. Nor is it inevitable that after an injury if an individual responds with pain-related fear they will definitely develop enduring pain (Leeuw et al. 2007). While there is evidence to suggest that fear plays a role when pain becomes persistent, the development of chronicity is due to pain intensity at the acute stage and distress (Pincus et al. 2006). Furthermore, while the constructs of the fear-avoidance model are correlated, there is no evidence for causal interrelationships (Crombez et al. 2012). Context and motivation for activity avoidance are largely ignored by the model, but these are important factors as people may confront feared activity if it is important to them even if they generally show avoidance for fear of pain/ damage (Pincus et al. 2010, Schmidt et al. 2015). Besides all the above, people may avoid activity, simply due to being unaware of acquired avoidance behaviour (not necessarily driven by fear or distress) (Pincus et al. 2010).

Conversely to activity avoidance, overdoing activity is also a significant problem in CP. Some people with CP may persist in doing activities despite pain, depending on the value they place on the goal they are trying to achieve (Crombez et al. 2012, Schmidt et al. 2015). After an episode of overdoing activity, people may experience increased pain, which leads to a need for rest until they feel better, and then the cycle starts again. This is called the overactivity/pain/rest cycle (Harding & Watson 2000). Over time, the periods of activity become shorter and rest progressively longer.

2.3.2 Self-efficacy and loss of confidence

CP can have an impact on confidence in everyday activities leading to low functional self-efficacy. Functional self-efficacy is ‘*the confidence a person has about their ability to perform functional activities*’ (Woby et al. 2007). Several studies have found that self-efficacy is a stronger predictor of disability than pain-related fear (Costal et al. 2012; Woby et al. 2007; Denison et al. 2004; Ayre & Tyson 2011).

Woby et al (2007) proposed a modified version of the fear-avoidance model (Figure 2-2) adding self-efficacy in the role of a mediator, shown by the dotted lines in Figure 2-2. According to the model, if functional self-efficacy is high, people are more likely to confront and perform activities even in the presence of high pain-related fear. However, in the presence of high pain-related fear and low functional self-efficacy, it is necessary to address both the cognitive factors (Woby et al. 2007). Studies show that low back CP patients demonstrate reduced disability, fear of movement and catastrophising following graded exposure. Thus, graded exposure can be effective to reduce pain-related fear and improve functional self-efficacy, as it requires people with CP to “engage in, and successfully accomplish, a feared activity” (Woby et al. 2007).

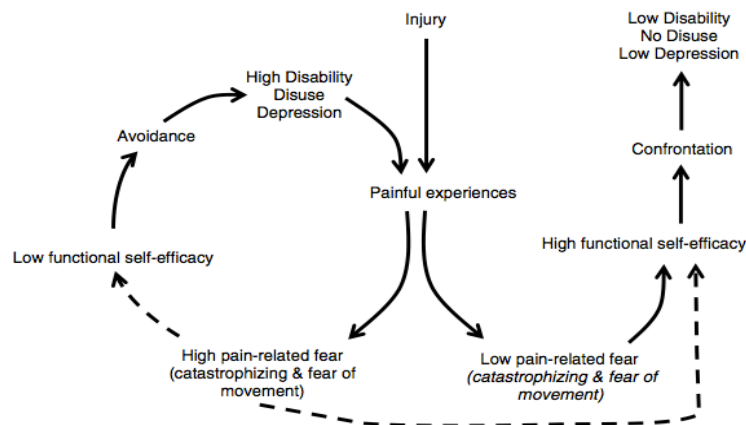


Figure 2-2. Revised fear-avoidance model (Woby et al. 2007) showing the role of functional self-efficacy. The dotted lines indicate that high pain-related fear can cause avoidance of feared activity when functional self-efficacy is low; however, in the presence of high functional self-efficacy, people are more likely to do feared activities despite the presence of high pain related fear. Reproduced with permission.

2.3.3 Worry

People with CP however do not predominantly report feeling fearful; they report persistent worry about the factors causing their pain and the associated negative consequences for themselves and others if it cannot be relieved (Eccleston et al. 2001; Aldrich 2000). Worry is described as “*intrusive, attentionally demanding, difficult to stop and distressing*” (Eccleston et al. 2001; Aldrich 2000) and leads to preferential attention to cues of possible pain (also

described as hypervigilance, but we avoid using this term since it implies that there exists a correct amount of vigilance). Worry is used to describe more everyday and possibly prolonged anxiety, rather than fear, which is more associated with specific events. Worry can also be implicated in increased avoidance in people with pain and can intensify pain and focus attention on it (Van Damme et al. 2006).

Generally, worry functions to promote problem-solving behaviour by anticipating possible consequences of action choices. When pain interferes with goal pursuit, making it hard for people to act according to their values, they are motivated to seek a solution. However, CP itself poses an insoluble problem because the pain cannot be resolved, and attempts to relieve it are unsuccessful. This paradox is framed as the misdirected problem-solving model, where the person with CP is the problem solver surrounded by many threats (Eccleston 2007). As efforts to solve the pain fail, a perseverance loop is formed, as shown in Figure 2-3, where increased worry strengthens the motivation to solve the problem. Repeated goal failures may then cause the psychological factors from the fear-avoidance model (e.g. fear, anxiety, catastrophising) to come to the fore (Crombez et al. 2012). The alternative is reframing the problem by accepting that pain cannot be cured and aiming for a better quality of life despite CP (Eccleston 2007).

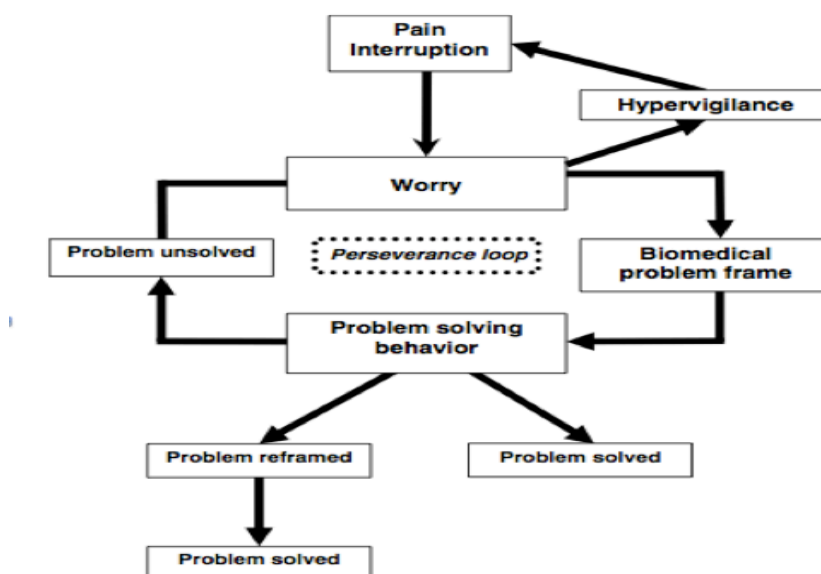


Figure 2-3. Misdirected problem-solving model (Eccleston 2007). Reproduced with permission.

2.3.4 Mood and depression

Pain intensity can contribute to increased anxiety and depression in people with CP. Depressive mood or depression in people with CP can in turn exacerbate pain and cause loss of motivation, disturbed sleep, lower activity levels and a detrimental effect on people's social life and recreational pursuits (Bair et al. 2003; Williams et al. 2006). Furthermore, an individual's

conceptualization of pain (e.g., feelings of helplessness, catastrophizing, low self-efficacy) can intensify pain experience, increase emotional distress, depression and physical dysfunction (Linton et al. 2012; Huijnen et al. 2010). Depression is a “*psychological problem characterised by negative mood, hopelessness, and despair*” (Linton & Bergbom 2011). While on average 52% of people with CP fulfil the criteria for clinical depression (Bair et al. 2003) and even more have depressed mood (Clyde & Williams 2002), they show important differences from those without comorbid depression and CP (Gatchel et al. 2007; Linton & Bergbom 2011; Pincus & Williams 1999). People with CP score more highly on somatic items but not on those assessing cognitive or affective depression in mainstream measures for depression (Pincus & Williams 1999) and their outlook is coloured by their appraisal of pain. Further, emotions such as anxiety, can be overlooked in assessing depression in people with CP (Pincus & Williams 1999). In spite of this, most studies still use standard depression questionnaires in pain populations and do not examine how differently people with pain answer them (Pincus & Williams 1999).

The most widespread model of depression in CP is that of Banks and Kerns (1996), which implicates the interaction of elements of personal vulnerability (diathesis) with “threats to well-being” (stresses) as cause for depression (Pincus & Williams 1999). Diathesis includes the assumed negative affect and personal vulnerability of the person with CP while stressors may include the pain itself or associated frustrations and losses (e.g. loss of function, work) (Pincus & Williams 1999). However, this model has not been subject to testing and remains at a very general level because of the unsatisfactory measures of depression and depressed mood in CP.

2.3.5 Anger and frustration

Frustration and anger are commonly reported among people with CP (Okifuji et al. 1999). Anger is recognised as an integral part of the CP experience and influences social, clinical and functional outcomes. Correlates of anger include higher pain intensity, less social support and poor sleep. Cognitive dimensions of anger in the context of CP include frustration at missed goals, blaming others for negative outcomes, and perceived injustice (Trost et al. 2012).

In addition to anger as a result of goal frustration (Karloly et al. 2007), frustration is also evident when pain interferes with an individual’s identity and role in life (e.g., as parent, spouse, friend, worker) and changes it (to person with CP). Individuals feel further anger and distress when they feel achieving their goals depends on pain relief (Trost et al. 2012) because for many people efforts at even partial pain relief fail, potentially trapping them in a cycle of *misdirected problem solving* described in Section 2.3.3 above.

Anger in people with CP can be a manifestation of attempts to claim control over situations or contexts that are difficult to deal with because of pain and related issues (Eccleston 2001). It can often have detrimental effects on health and treatment effectiveness as either the patient or healthcare provider withdraw from the therapeutic contract, fuelling more anger and frustration (Eccleston 2001).

2.3.6 Social factors

CP is a long, disruptive and aversive condition that can affect every aspect of the person's work, recreational and family life (Craig & Hadjistavropoulos 2004). People with CP often feel isolated, misunderstood and stigmatised in medical as well as broader social settings (De Ruddere & Craig 2016; Nicholas & Blyth 2016; Williams 2016). Stigma can be distressing and leads to further social withdrawal (Snelling 1994) and an impact on self-esteem (Williams 2016). People feel judged and misunderstood by colleagues for having to take sick leave or frequent breaks at work (Aegler & Satink 2009); at home, partners and family members may take over roles and responsibilities leading to a sense of loss or inadequacy in the person with CP (Snelling 1994). People with CP also commonly experience discrimination. In a study where students rated two remote potential exercise partners, shown in light-dot displays (Ashton-James et al. 2014) of an outline of the body in movement, the one demonstrating pain behaviour was rated less warm and less competent than the healthy one. If students detected that one of the two exercise partners was in pain they made less stigmatizing character judgments of that individual.

Early CP models based on Fordyce's operant theory (Fordyce 1976) focused on the role that other people including spouses, family and friends play in reinforcing behaviour which expresses pain (Keefe et al. 2004). For example, in operant models, a limp can be the result of an injury but if consistently followed by sympathetic attention, it can become controlled by this attention and persist, becoming maladaptive in the long term. The theory lacks any recognition of the role of pain beliefs in the control of behaviour, and makes substantial assumptions about what is positively and negatively reinforcing without attempting to confirm or disconfirm these assumptions. When discussed with people with CP, many of these appear to be inaccurate, and even to have opposite effects to those assumed (Newton-John 2002). Instead of the operant model, recent research is focusing on a broader perspective that acknowledges the role of emotional processes in social contexts (Cano & Williams 2010); this includes communication between patients and caregivers that can enhance interpersonal empathy, attachment and healthy emotion regulation.

2.3.7 Coping

CP is a stressor that is fundamentally threatening, interrupts attention and interferes with everyday life as discussed previously. Coping is defined as an “*effortful behaviour engaged in response to a stressor.*” (Van Damme et al. 2008). In CP, if pain is appraised as a threat (harmful), it produces a negative emotional response closely related to vulnerability leading to ‘*emotion-focused coping*’. If pain is alternatively appraised as a challenge, it can lead to ‘*problem-focused coping*’ (Wood & Neal 2007). Some literature also distinguishes between *active* and *passive* coping (Van Damme et al. 2008). Active coping attempts to control pain or function in spite of pain (e.g. distraction, activity management), while passive coping means withdrawing and not trying to control pain (e.g. rest, avoidance). Other distinctions are drawn between the ‘*approach*’ and ‘*avoidance*’ behaviours. Approach coping refers to engaging with the pain and its causes (e.g. identifying triggers for flare-ups), while avoidance coping refers to strategies of engaging in efforts to avoid pain (e.g. avoiding activities that increase pain).

However, distinctions like the ones above are artificial since they do not consider the context or the purpose (function) of certain strategies. For example, at times people may need to push to achieve certain goals instead of pacing, or spread activities out over a day instead of tackling them at once (Van Damme et al. 2008). Thus, Van Damme et al. (2008) propose that coping should be classified by function (what the coping behaviour seeks to achieve, in context) rather than features (e.g. active vs. passive). They use Brandstadter’s dual-process model of goal-directed coping where strategies are divided into two types: (i) assimilative, where people try to work out how to achieve the goal despite barriers, and (ii) accommodative, where people adjust expectations about their goals to reduce the internal tension experienced from trying to achieve unattainable goals. According to Van Damme et al. (2008), people with CP view coping as an attempt to pursue valued goals and activities. Based on the importance of the activity, the individual may try harder to achieve the task despite pain (task persistence). Schmitz et al (1996) adapted Brandstadter’s model to CP and ran a study comparing the two types of coping strategies. They found that the ability to adjust to goals flexibly in accommodative coping “*buffered the negative effect of CP on psychological wellbeing*”.

2.3.8 Activity pacing vs. avoidance

One of the strategies suggested by the literature and used by people with CP to manage their activity levels is called activity pacing. Pacing is an “*active self-management strategy whereby individuals develop self-efficacy through learning to balance time spent on activity and rest for*

the purpose of achieving increased function” (Jamieson-Lega 2013). It is a learnt strategy that can support people with CP to engage in valued activities, by breaking up activities based on time or quota (e.g., number of steps climbed). Pacing can thus reduce flare-ups and enable people to be self-directed and more effective in managing their pain, and be able to achieve what is valued through achieving a balance between activity and rest (Jamieson-Lega 2013).

Studies investigating avoidance, pacing and other activity patterns (McCracken & Samuel 2007) suggested that avoidance activity is similar to healthy coping. Pacing as a pain management strategy has been challenged by other authors in the literature (Karsdorp & Vlaeyen 2009) but although pacing has not been rigorously evaluated and there are variations in practice (Gill & Brown 2012), it is commonly mentioned by patients as a crucial principle for remaining active and is included in all professional and patient literature (Nicholas et al. 2013).

2.4 CP management

In the previous section, we presented the psychosocial barriers in CP. The literature reviewed showed how many psychosocial factors interact in determining the choices that people make to engage in physical activity. From the perspective of this thesis, it is essential to not just build an understanding of the psychosocial aspects of CP, their interaction and their effect on the individual with CP but also understand how people can increase and maintain physical activity despite pain. This understanding is crucial for the design of technology for CP self-management. To this end, in this section, we present how pain management programmes address the barriers to physical activity faced by people with CP.

Many formulations of psychological and physical therapies are used in combination or alone with the aim of increasing function and quality of life and reducing pain and distress in people with CP (Keefe et al. 2004). When medical techniques fail to resolve pain, the focus shifts to improving the quality of life of people with CP by working *“towards an optimal level of function and self-reliance in managing their persistent pain”* (BPS 2013). Pain management can support people with CP by addressing psychological factors presented in the previous section such as fear, anxiety, depression, and in some cases even pain levels (Eccleston et al. 2009).

Multicomponent pain management programmes offer a comprehensive approach to managing life with CP (Oslund et al. 2009). The British Pain Society (BPS) recommends pain management programmes (PMPs) as the *“treatment of choice for people with persistent pain that adversely affects their quality of life”* (BPS 2013). The recommended BPS guidelines state that, *“PMPs consist of education on pain physiology, pain psychology, healthy function and self-management of pain problems; and of guided practice on setting goals and working*

towards them, identifying and changing unhelpful beliefs and ways of thinking, relaxation, and changing habits which contribute to disability. Participants practice these skills in their home and other environments to become expert in their application and integration” (BPS 2013). PMPs are generally delivered in a group format and evaluation of outcome is recommended to be *“standard practice, assessing distress/emotional impact of pain, beliefs and thinking biases, range and level of activity, pain experience, health care use, and work status where relevant”* (BPS 2013). Delivery is based on psychological principles of behaviour change but involves a team of doctor, psychologist, physiotherapist, and often nurse or occupational therapist.

While attending PMPs, people with CP are encouraged to develop and maintain regular exercise routines that can help to build fitness and improve mobility and confidence in physical activity. People practice pacing and setting goals for activities, using cognitive therapeutic skills, relaxation techniques, and self-managing pain exacerbation (BPS 2013). The rest of this section discusses the main psychological therapeutic interventions for CP.

2.4.1 Cognitive behavioural therapy (CBT)

PMPs based on cognitive behavioural therapy (CBT) are the recommended treatment for people with CP (BPS 2013). There is good evidence for the efficacy of CBT compared with no treatment or treatment as usual reflected in outcome measures such as improvement in mood, activity levels and experience of pain (Eccleston et al. 2013). Evidence for efficacy of other psychological models is weak or lacking (Raine et al. 2002).

CBT is based on the biopsychosocial model of pain management described previously (Gatchel et al. 2007) and helps people to address unhelpful behaviour, cognitions and emotions through a systematic goal-oriented set of interventions (Kerns et al. 2011; Williams et al. 2012). It draws on various cognitive and behavioural techniques including education and information, behaviour reactivation, goal setting, cognitive techniques to challenge unhelpful thoughts and beliefs, relaxation and relapse prevention (Williams et al. 2012). However, which specific therapeutic mechanisms best predict patient improvement are unclear as treatment content, quality, length and outcome measures vary across different programmes (Vlaeyen & Morley 2005; Williams et al. 2012). The main components of CBT are discussed below.

Education and information

People equate pain with damage and in people who have CP this belief causes worry about the meaning of pain, avoidance of activities perceived as causing further damage, and rest. People expect pain relief and resolution from healthcare providers. An understanding of CP mechanisms and the structure and functioning of pain and pain pathways can help people to

shift their focus to rehabilitation and strategies for self-management of pain (BPS 2013).

Behavioural reactivation

Withdrawal from activity due to pain has a detrimental impact on people's function, social life, work and recreational activities. Through behavioural reactivation techniques, people with CP can work to increase activity levels towards enjoyable or desired goals and improve their sense of self-efficacy as they achieve their goals.

Often in behavioural reactivation programmes, people work on specific exercises or stretches and small increments to activity are gradually introduced (Koes et al. 2006; Hayden & van Tulder 2005). Exercise-only programmes are not explicitly linked to functional goals and hence may not be well suited to goal-directed activity in CP. Once goals are set based on people's everyday functional activities they are simplified into components addressed with exercise and gradual increases on baseline (Nicholas et al. 2013). The increases can be in terms of time, distance, speed or demand such as weight or gradient. Behavioural reactivation works best in association with other components of CBT. For example, a person may avoid movement because of fearful beliefs, which can be addressed by cognitive work in association with behavioural reactivation (Harding & Watson 2000).

Cognitive interventions

In the cognitive behavioural model, cognitions strongly influence behaviour and emotions. Developing an understanding of unhelpful beliefs and cognitive biases in the context of people's lives and their pain can help to change behaviours and cognitions. Reflecting on and reinforcing new helpful behaviours can then be done through behaviour experiments (Bennett-Levy et al. 2004). Cognitive interventions can shift the focus from fear, pain and depressed thoughts that lead to avoidance and catastrophising (Leeuw et al. 2007; Vlaeyen & Linton 2000) to achieving valued goals and a better life. Unhelpful beliefs can be addressed through providing the person with CP with pain-related information, addressing worry through problem-solving and supporting the person in attempting new feared behaviours (Eccleston 2007).

Relaxation

The aim of teaching relaxation techniques to people with CP is to decrease muscle tension due to CP (Craig & Hadjistavropoulos 2004). Early work on relaxation therapies included progressive muscle relaxation, biofeedback and education about the relationship between muscle tension and pain (Hadjistavropoulos & Williams 2013). Relaxation is not supported by randomised controlled studies (RCTs) as an intervention for CP (Knost et al. 1999) as there is little evidence of the importance of muscle tension under voluntary control in pain exacerbation

(Hadjistavropoulos & Williams 2013). Rather, more evidence in CP indicates that muscles that are far from the site of pain and not under voluntary control, become tense during movement (e.g. around the spine when bending) (Harding & Watson 2000). People with CP have more effortful movement because their muscles take more time to come back to baseline measures (Watson et al. 1997). While muscle tension can result from emotional stresses (Flor et al. 1992) and timing and coordination (Watson et al. 1997), the tension-pain model ignores psychological and emotional aspects. For example, there is evidence that anxiety can cause muscle tension in sites of pain in people with CP (Hadjistavropoulos & Williams 2004).

2.4.2 Exposure therapy

Exposure therapy is a well-established psychological treatment for specific phobias designed to reduce avoidance of feared stimuli by gradually exposing affected individuals to those stimuli until fear subsides; at this point they are exposed to a more feared stimulus, until avoidance is extinguished. Exposure may or may not be associated with a reduction in fearful beliefs and distress (de Jong et al. 2005; Woods & Asmundson 2008). Applied to CP, (Vlaeyen et al. 2001) it involves gradual increments of activities that are feared for their potential to exacerbate pain, increasing only when anxiety about doing the activity has subsided to a manageable level. Gradual exposure to activity can be further supported by education about what is and is not threatening, and by relaxation in the face of the feared activity (Vlaeyen et al. 2001). This is different from graded activity, in which activity is increased on a quota basis from baseline without reference to anxiety. Studies found that exposure therapy was more effective than graded activity or controls at addressing fear in people with CP (Vlaeyen et al. 2001; Woods & Asmundson 2008).

2.4.3 Acceptance and commitment therapy (ACT)

ACT is an “*acceptance and mindfulness-based psychotherapeutic intervention*” (Hayes et al. 1999). In ACT, people are encouraged to observe unpleasant emotions, sensations, thoughts and feelings without trying to alter them or becoming emotionally engaged with them; instead, they try to focus on the satisfying and rewarding aspects of their life (Dahl et al. 2004; McCracken et al. 2005). ACT works on the premise that struggling with pain exacerbates it, causing more distress and stopping individuals from doing activities important to them (McCracken et al. 2005). Conversely, acceptance of the pain leads to better emotional, social and physical functioning (McCracken et al. 2005). Recent studies have shown promising results and the potential for using ACT for CP management (Veehof et al. 2011; Eccleston et al. 2013)

Mindfulness

Mindfulness, one of the components of ACT, is the “*awareness that emerges by way of paying attention on purpose, in the present moment, and non-judgmentally to the unfolding of experience moment by moment*” (Kabat-Zinn 2002). It promotes awareness of emotions and physical sensations while maintaining an emotional detachment from them. It has been effective in reducing pain and emotional distress in uncontrolled trials for CP (McCracken et al. 2005). Clinically, it is often part of a mindfulness-based stress reduction (MBSR) programme and has benefitted people with low back pain (Morone & Greco 2007). MBSR has also been evaluated in combination with CBT principles as an intervention called mindfulness-based cognitive therapy (MBCT). Evaluation in depressed populations (e.g., Ma & Teasdale 2004) is promising and it is increasingly being used in clinical environments.

2.5 Considerations for developing technology for people with CP

In the previous sections, we discuss how psychosocial barriers affect physical activity uptake in CP and how pain management programmes use different psychological and physical therapies to address these barriers to support people in achieving a better quality of life. While pain management programmes (PMPs) can help people with CP to improve quality of life, many struggle to maintain the necessary lifestyle changes over the long term (Turk & Okifuji, 2002; Daniel & Williams 2010). Repeated follow-ups are difficult and expensive and there is a lack of clinical resources to meet demand.

Technology can be used to provide long-term support, but technological behaviour change interventions need to be adapted rather than directly translated from traditional methods involving a healthcare professional (Rosser et al. 2009). This is because (i) the interventions for CP discussed above target a range of issues, not just physical activity, (ii) it is not easy to make a decision on what elements are the most useful for patients and should get more importance (Vlaeyen & Morley 2005; Eccleston et al. 2009), so it is difficult to choose the parts that are most effective and leave out others, (iii) people interact differently with an individual than with technology such as a computer (Rosser et al. 2011), and (iv) direct translation leaves no room to innovate with the possibilities provided by technology beyond the obvious. Besides, it is important to understand why treatment gains are not maintained in the long run to build tools for long-term adherence to physical activity through technology. However, models of maintenance are often not specified in interventions and the assumption is that repeating the principles of behaviour change is sufficient for it to happen. But there is little evidence that adherence to pain management methods that are taught on PMPs underpin long-term success in behaviour change. On the other hand, if behaviour change had been established as new habits of

physical activity, then people would be more likely to continue the behaviours over the long-term.

There are also other influences on long term adherence of new behaviours that need to be acknowledged and can undermine self-management, such as intervention by family (e.g., do not do that if it makes you feel worse), broader social circles, work (e.g., either come back full time or retire on ill health), and access to welfare (Harding & Watson 2000). Long-term behaviour change and adherence through the formation of habits is discussed in the next chapter.

Also, while the psychosocial barriers are well explained in the literature, it is important to understand what strategies people use to maintain their activity despite pain and what are the barriers that they need to overcome specifically to self-manage physical activity and what motivates them to overcome these. However, most of the literature is from the perspective of clinicians and the technology to be designed needs to focus on the needs of people and the gaps that they currently perceive when they try to self-manage their physical activity (Beale et al. 2011). Routinely measured outcomes in treatments are often not those that are important to people with CP (Beale et al. 2011). For example, planning activities, quality of life, enjoyment and hobbies are important to people with pain but are not generally represented in evaluation of therapies. So while people with CP may show significant improvements over pre-treatment levels of managing their pain many dimensions of importance to them are left out (Beale et al. 2011). It is important, therefore, when designing technology to understand the dimensions most important to people with CP in making changes to their levels of activity (Beale et al. 2011).

2.6 Chapter Summary

This chapter discussed the psychosocial challenges faced by people with CP, and the biopsychosocial formulation of pain. We then presented the psychosocial factors that hold people back from physical activity include fear of movement, catastrophising, worry, preferential attention to pain, low self-efficacy, depressed mood, anger, frustration, low motivation or boredom (Nigg et al. 2008; Rejeski & Mihalko 2001) and other social factors. Models were also presented of how these psychosocial factors interact.

Pain management programmes (PMPs) and healthcare providers use cognitive and behavioural therapies to address the psychosocial barriers that affect people with CP, and to improve function and quality of life. PMPs that use CBT are the treatment of choice for CP (BPS 2013). PMPs teach patients the skills required to manage their pain independently (BPS 2013). Patients on these programmes are expected to make lifestyle changes such as regular physical exercise and use of pain management strategies (Turk & Okifuji, 2002). However, it is not a

straightforward process to convert the interventions for managing pain in people with CP (discussed in this section) to a technology to motivate people with CP to exercise (Vlaeyen & Morley 2005; Eccleston et al. 2009).

While there is a substantial literature on psychosocial factors affecting CP, a lot of the literature is from the clinician or practitioner point of view and not from the perspective of the person with CP (Beale et al. 2011; Osborn & Smith 2011). Further, as suggested by the biopsychosocial model, the way psychosocial factors combine to affect different individuals with CP is different and there is no single solution that can be applied to manage pain in everybody (Kindermans et al. 2011).

Next, we turned to the behaviour change literature to determine the best techniques to encourage people with CP to do more physical activity and maintain it in the long term. For this, the next chapter examines behaviour change theories in psychology and technology and their application in designing technology to support people with CP to self-manage physical activity.

Chapter 3 Background: behaviour change theories and frameworks for physical activity

In the previous chapter, the psychosocial factors implicated in CP and related therapies were discussed from the clinical psychology literature on chronic pain. We also highlighted that while psychological interventions used in pain management programmes (PMPs) are successful in the short term, the treatment gains from PMPs are not maintained in the long term self-management of physical activity in people with CP. Also, PMPs focus on overall self-management of CP, not specifically physical activity. To identify techniques supporting self-managed physical activity in the absence of physiotherapists, or for people who may not have access to physiotherapists, we looked at behaviour change research literature that informs many HCI technologies. Many behaviour change theories in the health psychology literature have been used on generally healthy people to mobilise healthier or less risky behaviours, such as increasing exercise, stopping smoking, or improving diet. In this chapter, we examine that literature to identify factors that may be applied in people with CP.

This literature can be useful for gaining insights into effective evidence-based behaviour change techniques for unsupervised self-directed physical activity. Identified techniques can be useful in designing technology after accounting for the difficulties faced by people with CP (stated by them from the literature) and adding CP-specific psychological components where these are needed (e.g. addressing anxiety about doing harm). Recently the importance of designing interventions using behavioural theory has been emphasised in the literature (Michie 2005; Brug et al. 2005) as it helps to identify the causes of behaviour and mechanisms of changing it. Basing interventions on theory fosters understanding of what is effective and can lead to more interventions that work based on proven, evaluated methods (Abraham & Michie 2008). Unfortunately, there is no clear guidance on choosing which of the multiple and overlapping theories of behaviour change to apply because of the lack of conceptual clarity in existing interventions and the theories and techniques underlying them (Abraham & Michie 2008). The theories have now been synthesised into a single model (Michie et al. 2011), resolving much of the lack of conceptual clarity (Michie et al. 2008).

In this chapter, we first examine behaviour change theories and techniques that predate Michie's model or are still used to bring about physical activity change in the general population to

understand commonly used theories, techniques and frameworks for designing such interventions in the behaviour change and persuasive technology literature. We also examine the role of habits in forming physical activity behaviours, recognised as a weaker component of behaviour change theories (Michie et al. 2011).

3.1 Theories and models of behaviour change in physical activity

Understanding and changing behaviours is complex and the research literature contains many interventions that aim to change behaviour (Michie et al. 2011). The multiple behaviour change theories fall into two approaches (Buchan et al. 2012): stage-based and cognitive-based. Stage-based models propose that to adopt complex behaviours such as increasing physical activity, individuals go through stages in a specific order; cognitive-based approaches propose that people use rational cognitive activity to control complex behaviours, with little or no attention to emotional factors.

In the area of physical activity (Williams & French 2011; Nigg et al. 2008) the most popular cognitive models are: social cognitive theory (Marks 2005; Bandura 1977), theory of reasoned action (Fishbein 1975), theory of planned behaviour (Ajzen 1991; Ajzen 2002), goal setting theory (Locke & Latham 2002), relapse prevention model (Marlatt 1984), health belief model (Baum 1997). These theories have many shared concepts, and some explicitly built on others. Among stage-based models, the transtheoretical model (Prochaska & Velicer 1997) is dominant. These theories are not described in detail here but their salient features, strengths and weaknesses are summarised in Table 3-1 and their strengths/ weaknesses for CP are highlighted in the last column.

Table 3-1. Theories of behaviour change for physical activity. The last column shows if/ how the theory or its constructs can be useful or are used in CP.

Name	Description	Strengths	Weaknesses	CP- physical activity
Theory of reasoned action (TRA)/ planned behaviour (TPB) (Ajzen 1991; Ajzen 2002)	Intention consists of attitude towards the behaviour and subjective norm or perceived social pressure to perform (or not) the behaviour.	Widely used to understand, evaluate and predict physical activity behaviour	-Not used to develop interventions (Hardeman et al. 2002) - Neglects emotion (Hardeman et al. 2002)	Physical activity in CP can be determined by emotion, neglected by TRA and TPB.
Social cognitive theory (SCT) (Marks 2005; Bandura 1977)	Includes intent to change and self-efficacy. Increased self-efficacy or reduced barriers effect behaviour change.	Self-efficacy is a predictor of behaviour as well as of behaviour change.	-Not evident which construct influences behaviour. Neglects emotion (Ashford & Edmunds 2010).	Self-efficacy mediates effect of fear on physical activity (Woby 2007)
Relapse prevention theory (RPT)(Marlatt 1984; Baum 1997)	Extends SCT to behaviour change maintenance by planning for addressing future barriers to behaviour to prevent/ recover from a relapse	Is more effective in preventing rather than maintaining (e.g. addiction)	- Focusing on reasons for failure might undermine self-efficacy (Williams & French 2011).	PMPs advise activity plans for periods of high pain intensity (setbacks) in CP.
Health belief model (HBM) (Rosenstock 1974)	Describes how increased perceived susceptibility to a threat or its perceived severity motivate actions to reduce such threats; Alternately how reducing barriers can increase likelihood of desired behaviour.	Can predict behaviour, cited in many interventions, but no intervention based on it was found (Bandura 1994).	- Perceived severity can lead to avoidance behaviour (Bandura 1994). -No clear links between components. Ignores factors such as social influence, habits and attitudes. -Neglects emotion	In CP, perceived susceptibility to and severity of the threat (pain) in increasing physical activity can lead to avoidance.
Goal setting theory (GST)(Siegert 2004; Jin 2010; Locke & Latham 2002).	People are more likely to change behaviour if they set themselves specific, meaningful goals.	Strengthen motivation. Interventions (Yelland & Schluter 2006; van Middelkoop et al. 2010).	-Setting vague goals/ goals at too challenging (or not challenging enough) can be demotivating.	Used in pain management programmes as part of behavioural reactivation.
Transtheoretical model of change (TTM)(Prochaska & Velicer 1997)	Design, implement interventions based on stage of readiness to change: 1. Pre-contemplation, 2. Contemplation, 3. Preparation, 4. Action, 5.Maintenance, 6. Termination. Move between stages depends on self-efficacy	Widely used in behaviour change interventions including persuasive technology.	-Weak supporting evidence (West 2005). Stages are arbitrary time periods. People can be in more than one stage at a time or transition quickly and in no clear order (Munro et al. 2007). -Neglects emotion.	No evidence to suggest that people go through defined arbitrary stages in pain management or of 'readiness to change' as useful to starting behaviour
Self determination theory (SDT) (Deci & Ryan 1985)	Describes motivation to change behaviour (active and passive) as influenced by innate needs of competence (self-efficacy), relatedness and autonomy.	Can successfully develop intrinsic motivation through external regulation to maintain behaviour.	- If the behaviour does not show enough autonomy, intrinsic motivation for long-term adherence can be affected. - Neglects emotion	

Behaviour can be described as a function of intentions, habits, emotions and situational constructs and conditions (Triandis 1977; Stern 2000). However, as shown in Table 3-1, most theories focus only on intentions as direct antecedents of people's behaviour and target influences on intention, i.e., motivations, beliefs and attitudes to change behaviour. For example, the theories of reasoned action and planned behaviour (Ajzen 1991) focus on peoples' beliefs that their attitude directly influences intentions and determines whether they change their behaviour (or not). Motivation is also an integral factor to the self-determination theory (Deci & Ryan 1985) which is used in gamification as discussed in the next chapter. Despite the focus on changing intentions in the theories above, intention is a modest predictor of behaviour change (Armitage 2001; Armitage & Conner 2005; Godin & Kok 1996) and many people do not act on good intentions despite seeing the merit of changing behaviour (Orbell & Sheeran 1998). Many barriers to behaviours such as increasing physical activity are not related to intention but factors that undermine actuation and ability to perform the behaviour, which need to be identified and targeted. Hence, non-performance of a behaviour could be related to the fact that the barriers to overcome were too much for the behaviour change construct to change it. Many people with CP have the intention and desire to be active but they are held back by psychological factors discussed in Chapter 2 such as fear of pain exacerbation and damage that override intention.

Perceived barriers in addition to perceived risk and severity of threat and perceived benefits to changing behaviour as determinants of behaviour change are also a focus of the health belief model (Rosenstock 1974) in Table 3-1. In the case of CP, there are two perceived threats: people might avoid some physical activity behaviours because of the threat of increased pain but avoiding physical activity also risks their condition and mobility getting worse.

Moreover, and most importantly, these theories do not address the emotional aspect of behaviour which can be a direct influence on intention formation (Triandis 1977). Intentions can be formed based on emotional response to the behavioural outcome or perceived risk (Triandis 1977). Emotional responses to a decision may include positive and negative responses. Fear, one of the big psychological barriers to physical activity in CP, offers a clear example of how emotions can interfere with behaviour (Verplanken & Holland 2002; Kahneman 2003). In extreme cases some of the behavioural outcomes and choices of performing behaviour can be non-conscious due to the influence of emotion and not be influenced by intention at all.

Addressing emotional factors is vital to successful self-management of physical activity in conditions like CP where despite intentions of engaging in more physical activity behaviours, people are restricted by the constant presence of pain and associated psychological and emotional barriers (described in Chapter 2). In addition, avoidance behaviour can be reinforced

by increased pain and setbacks in progress due to increased activity levels, which then hamper future efforts at increasing physical activity levels. As emotional factors are so important in the CP condition, theories and models focusing on self-motivation, beliefs and readiness to change are not sufficient to inform interventions for encouraging physical activity in people with CP.

Emotions such as fear in CP can be mediated by increased functional self-efficacy in doing behaviours (Woby et al. 2007). Self-efficacy appears in the social cognitive theory in Table 3-1, and has been shown to be effective in predicting both adoption and maintenance of physical activity behaviour in healthy adults (Ashford & Edmunds 2010). There is evidence that changes in self-efficacy can increase physical activity (Ashford & Edmunds 2010). The model by Woby et al. (2007) discussed in Chapter 2, proposed that people with CP are less likely to avoid activity or reduce activity levels despite a high level of pain related fear if self-efficacy is high. Ashford & Edmunds (2010) conducted a systematic review to disentangle how self-efficacy can be used in behaviour change interventions. They found that the highest self-efficacy levels were produced by providing feedback on past performance, comparing with others' performance and vicarious experience.

Other behaviour change strategies such as previous experience of behaviour (Gollwitzer 1999), specific actionable goals (Locke & Latham 2002) and strategies and plans for implementing the goals or intentions in different situations (Gollwitzer & Sheeran 2006) are better predictors of behaviour change than intention to change behaviour and are used in pain management programmes.

The other aspect that is neglected in the theories above is long-term adherence to behaviour and the formation of habits. There is evidence that intentions have reduced impact on behaviour where habit is strong in physical activity and diet-related interventions (Gardner et al. 2011) indicating that habit formation is an important goal for behaviour change. We discuss habits in Section 3.3.

These behaviour change theories also ignore the impulse to act that can come from a change in the environment that may work to facilitate physical activity behaviour (Thaler & Sunstein 2008). External factors such as rewards, incentives and anchoring are also ignored by the theories but are effective in adherence interventions and for long-term behaviour change (Dolan et al. 2012; Thaler & Sunstein 2008).

In the next section, we discuss application of behaviour change theories and the use of frameworks based on these theories to design interventions.

3.2 Applying behaviour change theories and frameworks

As discussed in the previous section, the theories most commonly used for encouraging physical activity in healthy populations show specific limitations in addressing CP. While some useful constructs were identified for use in physical activity for people with CP, applying the theories to designing interventions is not straightforward for the reasons described in this section.

Many behaviour change constructs in each theory: While behaviour change theories have many useful constructs that influence behaviour, these multiple constructs often overlap, making them complex and hard to test (Michie et al. 2011; Bartholomew et al. 1998). For example, self-efficacy and intention are central constructs in multiple theories including the theories of planned behaviour, protection motivation model and the health belief model. Further, distinguishing useful constructs from ineffective ones is challenging making it difficult to develop, evaluate and replicate interventions based on them. For example, in the health belief model, perceived severity of threat can result in avoiding behaviour (Bandura 1994) instead of causing it as expected.

To address the above problems, comprehensive behaviour change technique taxonomies have been created for comparing and documenting interventions. Michie et al (2008) further used the behaviour change techniques in their taxonomy of intervention components to conduct a meta-regression analysis evaluating the efficacy of individual techniques across interventions targeting physical activity and healthy eating (Michie et al. 2009). They found that both physical activity and healthy eating interventions were significantly more effective if they included self-monitoring with another self-regulatory technique (at least one of the following: prompt intention formation, prompt specific goal setting, provide feedback on performance, and prompt review of behavioural goals).

Primarily theories predict behaviour not behaviour change: Theories for physical activity behaviour change described previously primarily predict or explain behaviours (Michie et al. 2010;) and give information of factors that need to be modified for behaviour change (Michie 2005; Nigg et al. 2008). However, the determinant (predictor) of behaviour is not the same as the determinant of behaviour change (Bartholomew et al. 1998). For example, in theory of planned behaviour a positive attitude towards more physical exercise could mean that the person is happy with his/ her current exercise level rather than motivated to increase it.

Meta-analysis and meta-regression studies of interventions in physical activity and healthy eating in the general populations have identified the most effective behaviour change techniques for predicting change in such behaviours. However, these analyses are not just focused on physical activity (for example, they include studies of healthy eating) and are based on the

healthy population. They cannot be directly or easily applied to interventions in conditions such as CP as they do not address the associated psychological aspects.

To disentangle the effective behavioural constructs and provide guidance in devising interventions for behaviour change, Michie et al. (2011) designed the behaviour change wheel (BCW) as a comprehensive theory based intervention framework (shown in Figure 3-1). The BCW provides systematic guidelines for mapping behaviour change techniques that can be individually evaluated for effectiveness and the possibility of using an iterative approach for intervention design. The BCW (Michie et al. 2011) shown in Figure 3-1 consists of four levels. The innermost layer or behaviour system shown in green in Figure 3-1, also referred to as the COM-B model, is a representation of behaviour as an interaction of capability, opportunity, and motivation (Michie et al. 2011). To achieve behaviour change, at least one element from the behavioural model needs to be modified. The next layer (in yellow in Figure 3-1) shows the theoretical domain models (Michie et al. 2011; Cane et al. 2012) of behaviour change techniques to be applied by the relevant intervention to change motivation, capability or opportunity in the behaviour model. The red layer or the intervention system in the behaviour wheel (see Figure 3-1) encapsulates nine intervention type categories, which mainly target intentions; however, it includes strategies that can influence automatic actions and support habit formation such as persuasion. The outermost layer addresses “*actions by responsible authorities to enable or support interventions*” (Michie et al. 2011).

Whilst the BCW provides a framework to facilitate a systematic application of theories it also inherits some of the problems of these theories: i.e. emotion is given a limited role. While emotion is listed on the theoretical domains (in yellow in Figure 3-1), the BCW is based on, and has been applied to, behaviour change interventions for healthy populations (e.g., smoking cessation and public health interventions), in which emotional barriers are minimal or not investigated. Further, emotion is also not adequately represented on the BCW and primarily relates to motivation. As discussed in the previous chapter, emotions such as fear, worry and anxiety affect psychological and physical capability as well as limit opportunities in people with CP. This limits the application of the BCW in its current form, despite its advantages, to develop interventions to overcome psychological barriers and increase physical activity behaviours in people with CP. This is because pain is fundamentally threatening, demands cognitive resources and triggers anxiety and other emotions which emerge in many studies as the main predictor of functional activity, even more than pain intensity (Gatchel et al. 2007).

Maintenance of new behaviours is another shortcoming of most of the theories and models of behaviour change as discussed in the previous section, and thus of the BCW. To ensure long-

term maintenance of a new behaviour, it needs to become automatic and habitual. We address habits in the next section.

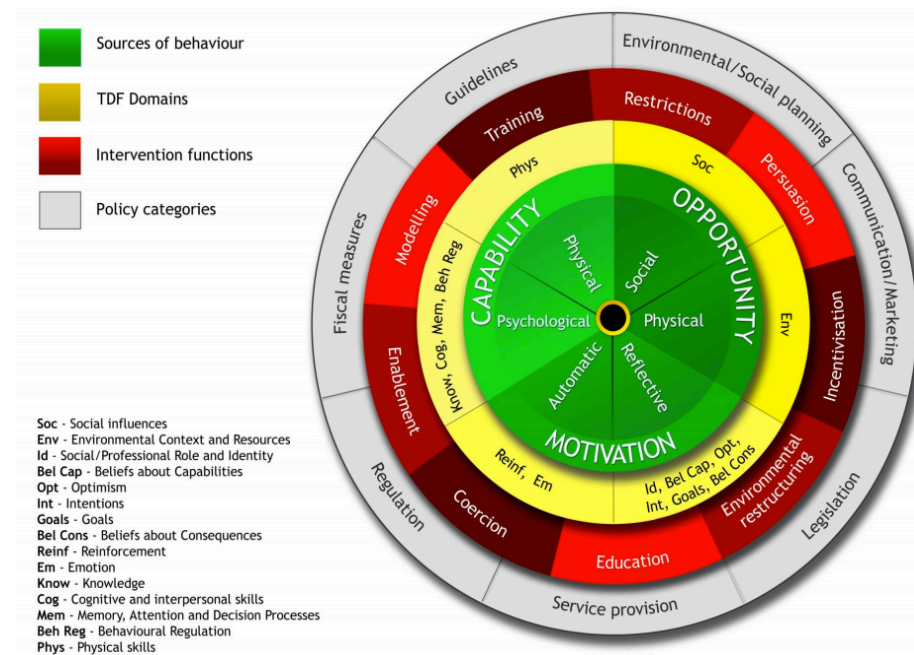


Figure 3-1: The behaviour change wheel (Michie et al. 2011) with theoretical domains for behaviour change implementation (Cane et al. 2012) mapped on it.

Frameworks have been proposed for designing technology to facilitate physical activity within the persuasive technology field as well. The cognitive theories of behaviour change summarised earlier have inspired requirements for persuasive technology that can help people change their behaviour (Consolvo et al. 2009; Oinas-Kukkonen 2012; Ritterband et al. 2009, Oinas-Kukkonen & Harjumaa 2009, Mohr et al. 2014)) However, they do not address the role of emotion in changing or maintaining behaviour. One of these models, the Fogg Behaviour Model (FBM) is like the COM-B model discussed earlier, but instead of opportunities it refers to triggers for technological behaviour (e.g., reminders, alarms). However, even in the FBM the main target for behaviour change is motivation and is more useful for targeting “tiny” habits and simple behaviours than complex ones with emotional barriers such as self-management in chronic illness.

3.3 Forming habits for long-term adherence to behaviour

For long-term adherence to behaviour and maintaining change, behaviour needs to become habitual. As factors that influence behaviour, habits (Darnton et al. 2011) can be viewed as automatic actions that are performed by individuals in stable contexts by gradually learning behaviour patterns and associations between the performed behaviour and its relationship with the environment (e.g., location of activity). They require minimal attention, decision, and

executive control. The influence of habits is especially strong when actions are performed in the same context, location or sequence regularly (Wood & Neal 2007).

New behaviours and habits can develop by automatic actions or because of conscious deliberative processes to start the behaviours (Verplanken & Holland 2002). This is based on the dual system theories of decision-making (Evans 2008), which postulate that decision making operates on automatic and reflective levels. While automatic decision-making is fast reacting based on context, reflective decision-making is rational, slow and deliberative. Behaviour change techniques working on both automatic and reflective decision making may be most successful (Verplanken & Holland 2002). With experience of behaviour, the influence of habits increases and that of intention declines indicating routinisation or automaticity.

Habits can be mentally represented as goal-action pairs influenced by context and strengthened by frequency of behaviour (Aarts & Dijksterhuis 2000). Indeed, 45% of our behaviour is performed in the same place everyday and 95% of our behaviour is automatic or controlled by “*cognitive unconscious*” processes (Darnton et al. 2011) or automatic processes described earlier. Habitual actions are more efficient, unintentional and require less active thought and deliberation, thus making cognitive resources available to other tasks (Bargh & Gollwitzer 1994). Habits can also be a result of existing elements such as lifestyles or convenience rather than an outcome of behaviour and contextual cues (Darnton et al. 2011). For example, in CP, protective behaviours are sometimes adopted non-consciously because of pain and become automatic. However, once rooted, routine practices are ‘locked in’ and people find them difficult to change (Darnton et al. 2011), partly because they take so little attention and demand few if any decisions. Therefore, in CP, disruption of habits such as protective behaviours or avoidance behaviours that have become automatic can be as important as the formation of new habits of physical activity.

While physical activity behaviours are reinforced during pain management programmes, they are unlikely to become habitual mostly because of the duration and frequency of the programmes or because they are not practised outside treatment settings. Thus, these new behaviours may fade after the pain management programmes finish, despite people’s best intentions to continue doing them, as highlighted in Chapter 2. Routinisation and habituation of physical activity in people with CP, supported by technology, could therefore help establish automatic habits of activity rather than requiring decisions about activity while coping with pain and emotional factors that interfere with physical activity.

Habit formation is most influenced by repetition of behaviour, which can serve to strengthen the associations between the cue to perform behaviour and the response, eventually making the

behaviour automatic. Further, in case of physical activity and rehabilitation, we know that to gain expertise a skill must be repeatedly rehearsed. The principles of massed practise (where a lot of repetitions are performed together) or distributed practise (where rest breaks are sprinkled throughout) can be used to form physical activity habits or disrupt bad habits where needed (Muratori et al. 2013). Behaviours that are more difficult may need different strategies, such as more planning and practicing of different parts of the behaviour. Linking behaviour to appropriate triggers in advance can increase the chances of performing the behaviour (Gollwitzer & Sheeran 2006) by forming implementation intentions or intentions to act that specify the circumstances in which a task will take place (Gollwitzer & Sheeran 2006). This can be especially helpful to break habits that are automatic or non-conscious. For example, deciding in advance to take the stairs rather than the lift when two or fewer storeys need to be climbed.

Behaviours also need to be repeated within a stable context to form associations between the behaviour and cues such as location, other people, and internal emotional states. Cues that drive behaviour are divided into “*cues-to-behaviour*” and “*cues-to-decision*” (Maddux 1997). Cues-to-behaviour are situational and can trigger automatic responses at times and facilitate easy habitual tasks (e.g. location of house keys near the door to remember to pick them up). Cues-to-decision can trigger thoughts about a specific behaviour that may lead to an action or prompt habitual responses (e.g., seeing shoes for running can trigger a reminder to run and prompt a decision to go running). Where context can be successful in building behaviours and habits, change in behaviour, such as building a new (desirable) behaviour (Verplanken & Melkevik 2008) or disrupting an undesirable one (Wood et al. 2005) can also be achieved by contextual changes. For example, joining a new job can disrupt existing habits such as exercise.

Habit formation is also influenced by positive reinforcement. Even small achievements can increase the feeling of satisfaction and strengthen habits by reinforcing a sense of control (Aarts et al. 1997; Lally et al. 2011). Thus, validating new behaviours can enable maintenance of long-term behaviour change (Rothman 2000) and associating a task with reward can help successful habit formation (Verplanken & Wood 2006).

3.4 Chapter Summary

Being more physically active despite having CP is a challenge for many people but physical activity is important to maintain function, as discussed in Chapter 2. In this chapter, we reviewed behaviour change literature for techniques and tools relevant to explaining and changing physical activity behaviours. Most behaviour change theories and frameworks reviewed tackle behaviour change by targeting peoples’ intentions, motivations and beliefs about a behaviour. It is difficult to apply the theories even though they include useful constructs

because the constructs overlap and there are many of them in each theory, making it difficult to apply the theory and to know which of the constructs within the theory are useful for designing interventions.

In terms of psychological factors, the theories primarily target motivation and self-efficacy. While these are important factors, they are not sufficient for interventions for encouraging physical activity behaviour in people with CP, which is affected greatly by emotional factors such as fear, anxiety and worry as seen in Chapter 2. Emotion is marginalised by the behaviour change literature, which has mostly been designed for targeting behaviour change in healthy populations. Where emotion is present (e.g., the behaviour change wheel), it is mainly applied to automatic motivation in healthy populations and not to other aspects such as psychological and physical capability, which can also be affected by it in CP.

The formation of habits was also discussed in this chapter and is an important aspect of long-term adherence to physical activity behaviours. We examined habits from the perspective of forming new physical activity behaviours and disrupting automatic behaviours such as protective movements in CP that people may be unaware of. Repeated behaviours in stable contexts and providing cues can be useful for habit (re)formation for physical activity behaviours in CP.

In the next chapter, we review technologies for supporting physical activity behaviours and physical rehabilitation to investigate how they address the issues identified here.

Chapter 4 Background: interactive technology to increase physical activity

In the previous chapter, we reviewed the various behaviour change theories and frameworks used in physical activity interventions and in behaviour change technologies. Several existing technologies have been designed to support and motivate people in doing more physical activity. These technologies provide a variety of functions discussed in the previous chapter, such as tracking, monitoring, giving feedback and information, increasing fun and engagement, and facilitating social interaction. While technologies to support self-management of physical activity show encouraging results for some chronic diseases (Mynatt et al. 2010), they fall short of addressing psychological issues in CP discussed in Chapter 2 (e.g., fear of movement, altered proprioception, loss of confidence and low self-efficacy). This may be because most of these technologies are based on the behaviour change theories discussed in the previous chapter and therefore they focus primarily on motivation and do not address other emotions specific to CP.

Nevertheless, we review existing technologies for encouraging and supporting physical activity behaviours in people with CP, chronic illness and the general population in this chapter. The aims of the review are to understand what exists and can be reused and what are the gaps in technologies designed to support physical activity behaviours in people with CP, other chronic illness and the generally healthy population. We also reviewed technologies to identify gaps that are important to address for self-management of physical activity in people with CP, especially related to the psychological and behavioural factors specific to CP, identified in Chapter 2.

Existing technologies to promote physical activity are divided for this review into (i) Internet-based information and communication technologies, (ii) ubiquitous technologies for self-awareness and self-monitoring activities, and (iii) situated technologies to support physical activity reactivation.

4.1 Internet-based information and communication technologies

One of the biggest impacts of technology development on CP physical activity self-management is information accessibility through increased access to the Internet. Online Internet-based interventions are freely available to people with CP and provide valuable resources and means for pain management support despite limitations like time, patient mobility and location (Bennett & Glasgow 2009). For this review, we divide Internet technologies into pain-related

websites, computerised and online cognitive behavioural therapy (CCBT) interventions, and remote monitoring and remotely supervised training technologies.

4.1.1 Pain-related websites

Internet-based information is a cost-effective method to address the needs of a large patient population through websites and Internet-delivered psychosocial or behavioural therapies. These resources provide information about a combination of pain, pain management, and behaviour change and may be monitored by therapists/clinicians or be completely automated (Buhrman et al. 2004). The number of pain-related web resources has increased substantially according to recent reviews (Polomano et al. 2007). Delivery of pain-related resources has also been done through smartphone applications (apps) that contain information about pain and pain reduction by physical methods. Some (e.g., Pocket Therapy, www.scavomed.com) include exercise recommendations to strengthen and improve movement range and provide exercise demonstrations mainly through a series of photographs or videos in a few cases. However, concerns have been raised about information accuracy, quality and regulation of pain-related information on the Internet (Corcoran, Haigh, Seabrook & Schug 2009). For example, 27 CP websites featured in the top search results across common search engines, was rated as poor or fair quality; only 2 were rated as excellent or very good (Corcoran et al. 2009). Despite the poor quality of information, evidence suggests that Internet-based interventions aimed at chronic conditions are effective and can support people in improving behavioural and clinical outcomes (Bender et al. 2011; Rosser et al. 2009). However, only providing information without any cognitive behavioural content is not enough to achieve complex behaviour change (Griffiths 2007). Further, information alone cannot provide the real-time clinical help valued by people with pain during physical activity sessions (Rosser et al. 2011).

In addition to information provision, the Internet provides social support through niche online support groups and social networks for a range of conditions to exchange information and advice (Rodham et al. 2009; Corcoran et al. 2009). For example, a qualitative study of message board postings for people with complex regional pain syndrome over a 4-month period found that people used it for support and to express their emotions. The board helped people to feel less isolated and connect with others in a similar situation (Rodham et al. 2009; Corcoran et al. 2009). However, some of the message boards and sites are unregulated or user-regulated so they may provide unreliable information. To overcome this problem, some pain management programs have integrated social support groups along with other Internet-based treatments, and users have found them useful (Ruehlman et al. 2011; Bender et al. 2011); these groups are formal, highly regulated and usually closed (with only member access).

4.1.2 Computerised and online therapy

Computerised cognitive behavioural therapy (CCBT) is a self-help option that can be delivered over the Internet or using CDs and offers patients the potential benefits of cognitive behavioural therapy (CBT) with reduced therapist involvement and thus cost. For mildly disabled and distressed patients, CCBT has been found to be as effective as therapist led CBT on a number of outcome measures (Kaltenthaler et al. 2006) and several studies report high satisfaction for CCBT services for those completing treatment (Waller 2009; Kaltenthaler et al. 2006; Kaltenthaler et al. 2008; Ormrod et al. 2010).

In CP, web-based CCBT has been used in the Web-based management of Adolescent Pain (WEB-MAP), through an interactive pain management training website featuring therapist involvement (Palermo et al. 2010). The website included eight CBT-based modules on topics such as pain education, relaxation, cognitive skills, and management of negative emotions. Therapists rated assignments done by participants. Parents also had access to training for positive coping, reward systems, modelling and communication skills. In a randomised controlled trial WEB-MAP participants demonstrated significantly increased function and reduction in activity limitations at post treatment compared to a control group even at 3-month follow up. However, interventions like WEB-MAP are intensive and demand time and effort from clinicians or therapists, which can be limited.

Other successful CCBT applications developed for conditions other than CP are Beating the Blues (Cavanagh et al. 2011) which is commonly prescribed by the NHS for depression and anxiety and successful on clinical measures (Kaltenthaler et al. 2006), Fearfighter (MacGregor et al. 2009) for phobias with evidence of high efficacy and Moodgym (Kaltenthaler et al. 2006) for depression, with limited evidence of efficacy for behaviour change. Advantages of CCBT-based treatments include convenience and ubiquitous access, and they are demonstrated to be effective in controlled settings (Andersson & Cujipers 2009). However, they have a relatively high dropout rate (26%) compared with traditional treatment (14%) (Macea et al. 2010; Bender et al. 2011), much as other online interventions. In CP, while CCBT is effective for working on some psychological factors such as addressing depression or fear, it does not provide real-time support during exercise such as addressing fear while doing a movement. In traditional settings, such reassurance provided by physiotherapists is valued by people when doing physical activity. Some apps aim to replicate content reported in cognitive behavioural interventions trials (e.g., Habit Changer: Pain Reduction, www.habitchanger.com). Unfortunately, these generally restrict themselves to describing the mechanics of behavioural exercises, and not on delivering the content within an appropriate framework (Rosser et al. 2011).

4.1.3 Remote monitoring and remotely supervised training

Remotely delivered healthcare services can also provide cost-effective opportunities for managing CP (Rosser et al. 2011; Cuijpers et al. 2008; Buhrman et al. 2004). Such solutions are predominantly modelled on traditional face-to-face pain management and hence have the same drawback that they do not address problems with long-term self-management of CP (Brattberg 2007; Buhrman et al. 2004). Longer pain management programmes produce better pain management outcomes but are more expensive and require more resources in terms of healthcare professionals (BPS 2013). Self-management technology can offer indefinite pain management support for self-managing CP and is a cost-effective alternative.

4.2 Ubiquitous technology for Self-Awareness & Monitoring Activity

Ubiquitous computing systems have been designed, built and evaluated for increasing physical activity in a wide range of behaviour change interventions, and have been used in a variety of different ways. For this review, we divide this section into (i) smartphone apps for self-monitoring of physical activity for CP, (ii) wearable activity sensing applications and (iii) biofeedback applications for physical activity.

4.2.1 Smartphone apps for self-monitoring of physical activity for CP

Many smartphone apps use self-monitoring and goal setting that have been identified by the behaviour change literature in Chapter 3 as important for supporting physical activity behaviours. Monitoring apps (e.g., CP Tracker, www.chronicpaintracker.com; *My Pain Diary*, www.chronicpainapp.com) allow users to log and track data such as mood and pain and provide pragmatic reminders such as for medication and medical appointments. Activity goal setting and tracking apps (e.g., WebMD PainCoach, www.webmd.com/webmdpaincoachapp) developed with healthcare professionals allow self-monitoring of activity and pain. The PainCoach app also provides tailored information about pain and activity related to personal goals and motivations of the user in addition to pain and activity related information. Other self-monitoring apps (e.g., Google PACO www.pacoapp.com) allow personalised monitoring for specific activities (e.g., exercise) and query user data to identify relevant factors. While such apps are promising for logging and self-monitoring physical and psychological states, they offer little psychological support and do not engage with counterproductive behaviour in CP (e.g., guarding). Also, none of the apps listed above gives real-time feedback for physical activity.

An authoritative review (Rosser & Eccleston 2011) explored available smartphone apps for CP self-management and reported that apps did not address CP-relevant psychological and

behavioural issues such as anxiety and worry about doing activity. Further, of the 111 apps found when conducting the review, 86% did not include any input from healthcare professionals in their design or content, further raising the question of regulation of healthcare apps.

4.2.2 Wearable activity sensing and feedback behaviour change applications

Various studies have been conducted to investigate physical activity support through sensor-based tracking and related feedback. Activity tracking smartphone apps for CP have been discussed in the previous section. Here, we review wearable applications, designed for physical activity populations other than CP to investigate successful techniques and strategies. Many of these applications use elements from behaviour change theories such as goal setting and gamification strategies based on the *self-determination theory* discussed in Chapter 3. Gamification or the use of elements of games in non-game contexts can make physical activity more enjoyable and motivate users to be more active (Zuckerman & Gal-Oz 2014, Groh 2012). To increase or maintain intrinsic motivation through gamification three important principles (Deterding et al. 2012) are: (i) relatedness or the need to interact and connect with others (e.g., social sharing of achievements); (ii) competence or the need to be effective and master a problem in a given environment (e.g., setting/ achieving realistic goals); and (iii) autonomy or the need to control goals (e.g., self-setting goals). To be effective, goals need to be well structured and achievable, for which they may need to be broken down into small and doable tasks (Groh 2012). This aspect is like pacing to achieve activity goals discussed in Chapter 2. However, some level of challenge may be necessary for engaging the user, as suggested by the *flow theory* (Csikszentmihalyi 1992).

Activity tracking applications (e.g., *Ubifit* (Consolvo & McDonald 2009), *Flowie* (Albaina et al. 2009) and *Fish'n'steps* (Lin et al. 2006), *pocket Pikachu* (Fogg 2002) and *Chick Clique* (Toscos et al. 2008)) use goal setting to motivate people of different age groups to increase the amount they walk each day by tracking progress towards goals using wearable sensors such as pedometers. These applications reward progress towards goals through using positive imagery which increases usability and pleasure in using the application (Tractinsky 2000) and is associated with increased feelings of self-efficacy (Groh 2012, Ritterband et al. 2009). Results of evaluating these methods of feedback in a 12 week trial of the *Ubifit* system showed that people were active while using the app though it was not clear whether new habits had formed (Consolvo et al. 2009). *Fish'n'steps* provided positive feedback and incentives not just for goal achievement but as progress was made towards the goal. Results showed that 14 of the 19 participants who completed the study continued to complete more steps than in the baseline. This application also tried the use of negative feedback, which was unsuccessful and caused

participants to ignore the application (Lin et al. 2006). Some of these applications allowed sharing of goal achievement, which people found was motivating and provided a benchmarking and stimulating challenge (Lin et al. 2006; Consolvo & McDonald 2009; Toscos et al. 2008). Social sharing can be useful for technology aimed at CP to address social isolation faced by people with CP.

While gamification is a good starting position to motivate regular health behaviours, it may not be sufficient as a means to create sustainable health behaviours as when people lose interest in the game, they may also lose interest in the new health behaviour that was established through the use of the game (McCallum 2012).

A recent wave of commercial products are using the sensors integrated into wearable devices (Patel et al. 2012) to infer activities and physiological states. In combination with smartphone apps and web dashboards these products are used for tracking fitness (e.g., Nike+) and wellness goals (e.g., Jawbone UP, Fitbit Flex). Other activities beyond walking and running can now be recognized: for example, automatic monitoring of repetitive exercises (e.g. weight training with RecoFit system's arm worn inertial sensor), discriminating between exercise and non-exercise periods and counting exercise repetitions (Morris et al. 2014). Beyond facilitating and promoting physical exercise, sensors are being used for other clinical purposes, e.g. to support gait rehabilitation in Parkinsons disease (Casamassima et al. 2013). Increasingly, sensors are used to monitor and raise awareness of body postures and sedentary behaviours such as prolonged sitting. The Lumo Lift (www.lumobodytech.com/lumo-lift) and the iPosture (www.iposture.com) are commercially available ubiquitous sensor applications for monitoring posture and providing vibrotactile feedback when people slouch based on a calibrated personal standard. Lumo-lift additionally provides an app for activity tracking posture coaching. Online reviews indicate that people find these devices easy to use.

4.2.3 Biofeedback for monitoring and controlling physiological states

Besides activity sensors, ECG, EMG, or other biofeedback sensors have also been used for physical activity applications to monitor the person's heart rate and muscle activity during exercise to support people to exercise within a healthy range (Newbold 2015; Hermens 2008). Biofeedback has also been shown to be successful, particularly in the treatment of anxiety and negative mood (Henriques et al. 2011), depression (Karavidas et al. 2007), stress-related CP (Hallman et al. 2011) and fibromyalgia (Hassett et al. 2007). Biofeedback can increase self-awareness by allowing the direct observation of a person's physiological state. It is widely used in relaxation training to reduce symptoms of stress. Clinical studies involving clients receiving CBT treatment for stress-related conditions such as depression, insomnia and Post-Traumatic

Stress disorder (e.g. Reiner 2008) revealed that the device helped to significantly reduce anxiety, anger and sleep difficulties.

Therapeutic apps for teaching behavioural skills related with relaxation are also available; these apps support techniques such as diaphragmatic breathing and progressive muscle relaxation (Morone & Greco 2007; Zautra 2010). Based on evidence suggesting that biofeedback can be useful in pain therapies (Nielson & Weir 2001), some apps utilise it to teach regulation in areas such as muscle tension, respiration, and heart rate by using real-time feedback (Morone & Greco 2007). This is done by using a wearable sensor to capture data (e.g. breathing, heart rate) which is sent through a mobile device to store and display it (Zhang et al. 2010; Liu et al. 2011). Newbold et al. (2015) use sonified rhythms to pace movement and synchronise it with breathing. Preliminary studies show promising results for such systems.

Other apps use the phone's global positioning system to monitor breathing using the rate at which the individual's stomach rises and falls, measured by a Smartphone placed on the stomach. For example, *BioBelly Interactive Breathing, Relaxline* teaches diaphragmatic breathing by using the sensor data to provide real-time audio and visual feedback. However, while this app shows potential, no empirical reviews were found and its efficacy is unclear. Some therapeutic apps facilitate relaxation by guiding and pacing breathing exercises ((e.g., *BreathPacer Larva Labs, New York, NY*); such apps establish an individualised breathing rate based on user height through the use of animated visual and audio cues that guide the development of relaxed breathing. However, appropriate studies of efficacy need to be conducted in the general population as well as in CP.

4.3 Situated technologies to support physical activity rehabilitation

Rehabilitation is a challenging process because of (i) lack of motivation and boredom caused by the repetitive nature of activities and (ii) the need for support and continuous monitoring (Bongers 2010). We discuss this section by dividing it into exergames for physical rehabilitation, virtual reality applications for mindfulness and distraction, activity sensing technologies for everyday home use and (iv) frameworks for self-management technology for physical activity.

4.3.1 Exergames for physical rehabilitation

Several research projects are exploring movement-tracking systems for interactive physical therapy. Many of these systems involve exergames combining physical rehabilitation with 'serious games' for the purposes of training and education (O'Huiginn et al. 2009; Perry et al. 2010). These exergames use motion tracking technology and other multimodal inputs to

automatically track exercise and other physiological measures and give multimodal feedback about performance of the activity through game features.

Schönauer et al. (2011) developed exergames for lower back and neck rehabilitation of people with CP (see Figure 4-1). Patients used the game at the clinic where physiotherapists set goals and baselines for the game and monitored patients while they were engaged with the game. Preliminary results after the training showed lower disability and pain intensity scores and an increase in walking ability. The game was tested with a Kinect system and a full body motion capture suit (MoCap). Though the precision in monitoring provided by the Kinect was lower, it provided an adequate substitute for the MoCap system which is unsuitable for self-managed rehabilitation as it is expensive, uncomfortable and cumbersome to wear (Chang et al., 2012; Schönauer et al., 2011). A later version of the exergame (Jansen-Kosterink et al. 2013) was evaluated with ten pain patients over 4-6 sessions across four weeks, in laboratory settings in the presence of a physiotherapist. Results of the evaluation showed that participants enjoyed the game and showed significant motor improvement.

While the games addressed motivation, they were designed for clinical rehabilitation use in presence of physiotherapists and not for self-managed physical activity; they did not address critical psychological issues in CP that were highlighted in Chapter 2, such as fear and anxiety associated with movement. While the exergames incorporated many behaviour change constructs such as monitoring, setting goals and measuring progress, the control for setting goals was with the physiotherapist. Further, they did not address the problem of avoidance of movements or activity through misconceptions or anxiety. Instead the games were based on a rehabilitation model where correction of specific movements and increasing fitness were the goal, rather than increasing overall engagement in everyday activities and developing long-term habits of physical activity

Exergames developed for other conditions such as stroke therapy mainly use commercially available consoles (e.g., Nintendo Wii (Bongers & S. Smith 2010; Hanneton & Varenne 2009; Yong Joo et al. 2010) and Playstation 2 Eyetoy (Rand et al. 2008)) in clinical settings where people do physical activity while being closely monitored by physiotherapists.

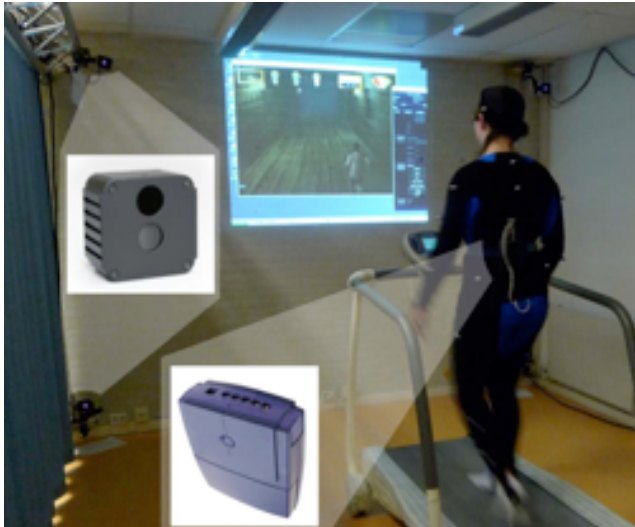


Figure 4-1: CP rehabilitation system with MoCap (Schönauer et al. 2011). Reproduced with permission.

Anecdotally, some people with CP report using pleasant experiences to help them with pain and pain-related anxiety and tension, while others describe being unable to engage because of pain interrupting and demanding attention (Legrain et al. 2009). This suggests that there is potential within exergames for a beneficial and enjoyable experience for people with pain, but a better understanding is needed. For example, the motivation with points gained or levels achieved may not be suitable for people with CP, but the option of making games out of activities that are meaningful to them (Burke et al. 2009) is useful and is supported by behaviour change literature (Nigg et al. 2008).

Mini-games have been developed for conditions such as stroke rehabilitation (Alankus et al. 2010) or cerebral palsy (Geurts et al. 2011), for use at home using standard Wii remotes and webcams. Developers of games aimed at specific conditions such as stroke recommend that games for self-management in the home should adapt to the abilities and goals of the user to be successful (Alankus et al. 2010). Geurts et al. (2011) designed and developed mini-games for people with motor disabilities illustrating the feasibility of commercially available input devices as game controllers; sensors used by commercial consoles such as the Wii and Eyetoy can be held like objects in the real world (e.g. a tennis racquet) and give a feeling of comfort and familiarity to the user (Bongers 2010).

Developers of rehabilitation games also emphasise the importance of adjusting game parameters to individuals' skills and development goals for optimum gains (Geurts et al. 2011). For example, Colombo et al. (2007) used a robotic device for arm rehabilitation where the patient practised moving a coloured circle from its initial position to a goal position (Colombo et al. 2007). Haptic glove-based games including scenarios where users scare away butterflies, play the piano, and squeeze pistons were developed to improve finger flexion and extension (Huber

et al. 2008; Jack et al. 2001; Choi 2011). To practise activities of daily living or target specific muscle groups, some games are designed to help with manipulating objects in a 3D world (Yeh et al. 2005), do training exercises modelled on everyday tasks (Sanchez et al. 2006) and exercises for arm reaching motions with audio-visual feedback (Chen et al. 2008). Riablo (www.corehab.com), a commercial rehabilitation system, allows clinicians to remotely monitor patients' physical activity with accelerometer data sent over the Internet.

Commercial consoles such as the Wii and Kinect have also been used to prototype games to promote physical activity in older adults (Romero et al. 2010). These movement games provide multimodal feedback (visual, haptic, verbal and music) and are cheap, ubiquitous and accessible. A randomised controlled trial (Crotty et al. 2011) conducted with 44 patients found that older inpatients made more improvements in balance and mobility using the Wii fit for physical therapy compared to conventional physiotherapy. Rehabilitation studies using the Wii are closely supervised by a physiotherapist because the games are not designed for rehabilitation and using the controller inappropriately or even getting too immersed in the game can cause injuries (Hanneton & Varenne 2009; Yong Joo et al. 2010).

Some physical rehabilitation applications use multisensory feedback to augment sensory perception and provide information to transform a generally frustrating experience into a more rewarding one (Jung et al. 2006; Lam et al. 2015). The feedback design mainly focuses on information about physical capabilities rather than addressing body perception and emotional barriers to activity.

Recently, researchers have started a debate about factors that are useful and desirable in rehabilitation games (Alankus et al. 2010), including identifying target users (so design can be tailored to the population), visibility (mapping user action to intended goal), and appropriate feedback (Jung et al. 2006) and considering game play that is meaningful and challenging to the user as important components for serious games (Burke et al. 2009). It is difficult to determine the long-term efficacy of movement related video games for physical activity promotion and behaviour change in people of all ages due to limited evidence (Biddiss & Irwin 2010; Saposnik et al. 2010).

4.3.2 Virtual Reality applications for mindfulness and distraction

Virtual reality (VR) systems have been found to be somewhat useful in treating acute pain (Botella et al. 2008;). While VR has not been used in any big studies of pain management (Mahrer 2009), there is support for VR as a useful tool for CP rehabilitation in some preliminary studies (Feintuch et al. 2009; Wiederhold 2007). Gromala et al. (2011) proposed the use of

meditation and biofeedback within a VR application for CP during a walking activity to address psychological barriers to activity. While this application addressed psychological barriers, it was only applied to walking and not to other feared activities. Also, despite the interesting approach and evidence of its success for acute procedural pain (Markus et al. 2009), there is weak evidence of the effect of mindfulness meditation within CP (Zeidan et al. 2012), due to the complexity of the condition.

VR is promising because it is immersive and capable of providing multisensory feedback (Kline-Schoder & Kane 2004) making it demanding of attention and emotionally engaging. However, most applications deal with distracting effects rather than changing long-term behaviour. One study with 14 participants, tested the efficacy of virtual reality against conventional exercise in two groups of patients over 6 weeks (Sveistrup et al. 2003) (i) in rehabilitation of chronic frozen shoulder pain and (ii) in balance retraining after traumatic brain injury. The patients undergoing VR training made more progress on all outcome measures.

The use of VR has also been shown to be effective in situations of sudden increase of pain. A prominent example is *Snow World*, a VR application that was used in burns wards during wound care and patients reported a large reduction in pain during the procedure (Markus et al. 2009). There have been promising trials of *Snow world* exposing people with CP to repeated trials of a highly engaging virtual environment to increase their confidence in using distraction for pain control (Keefe et al. 2012) but this research is still in its infancy and also does not target physical activity.

4.3.3 Activity sensing technologies for everyday home use

Recently the role of digital technology in designing support for the integration of physiotherapy with everyday life has been explored as there is an increased focus on self-managed approaches, not just in CP but other conditions such as stroke and post-operative rehabilitation. These explorations are in early stages and there are few examples of rehabilitation technologies designed for the home environment. This is because designing rehabilitation technology for everyday life contexts can be challenging in the rich, varied and complex environments of individual home environments (Axelrod et al. 2009).

In the case of CP, home rehabilitation studies have been conducted as part of the SMART2 project to support the self-management of CP (Duggan et al. 2015). The SMART2 system consisting of a stationary home hub (touch screen computer) and mobile device was trialled in the homes of 8 CP patients (Duggan et al. 2015). Participants could set up daily activity goals on the home-hub, receive reminders and log starting and stopping an activity through the mobile

device. The mobile device would track and record the step count and time spent on each activity and transfer the data to the home hub, which allowed them to review their levels of exercise, pain and mood and the number of activities completed thus providing feedback and motivation for everyday activity. Participants reported that they liked the system, especially the goal setting and feedback aspects. While this system provided a good example of using self-management technology to support and facilitate increased activity in the home, it primarily focused on providing motivation, not real-time or psychological support while people were doing the activity itself. Also, the system was based only on tracking step count and not any other body movement for which people could need reassurance or encouragement to address any emotional factors in doing the movement (e.g., fear of exacerbating pain due to bending or reaching).

Bagalkot et al. (2012) explored technology prototypes for the integration of rehabilitation technologies with everyday activities and in everyday contexts of the rehabilitees. Through four design sketches, they investigated how people could use technology personalised to their everyday activity to track physiotherapy exercises in their own home. For example, by inserting accelerometers in a mat on a swing to track the number of knee exercises or an exercise mat with force sensitive sensors to detect the performance of exercises on the mat, designers attempted to motivate adherence to physiotherapy exercise. Participants were rewarded for doing their recommended exercises through ambient LEDs placed in objects that people valued and placed in prominent places. These examples were mainly reported as design explorations through reflections of the researchers and not evaluated for efficacy in motivating exercise.

Another participatory design study was conducted as part of the Motivating Mobility project (Balaam et al. 2011) to understand motivation and rehabilitation needs of people after stroke with the aim of constructing and deploying interactive systems to meet these in the home. They aimed to support individual motivations (e.g., playing chess, playing with your child) to create value in rehabilitation. The aim of the system was not to create and evaluate a system for wide use and deployment, but to draw lessons and design guidelines to gain a better understanding of motivation, drawing from case studies, for home rehabilitation support. While motivation is important for self-rehabilitation in the home, other emotional factors need to be addressed in CP such as fear and anxiety of pain exacerbation as indicated by the literature in Chapter 2.

Both the above cases of technology development (Bagalkot et al. 2012, Balaam et al. 2011) were proof-of-concept technologies integrating exercise into specific activities that were enjoyed by individuals (e.g. moving a digital chess piece using a squeeze sensor, or exercising by putting a ball into a ball pit for fine motor skills). While both technologies took motivations of individuals into consideration during rehabilitation and augmented exercise strategies, they

were not designed to facilitate everyday functional activities. Another type of system used to encourage physical activity in the home of elderly people was a recommender system in a digital photo frame mounted in a commonly used room (Rist et al. 2015; Seiderer et al. 2015). This system's aim is to increase wellbeing in users but it does not do real-time tracking of activity or address emotional barriers to activity.

One of the important strategies for managing pain in CP literature was pacing as discussed in Chapter 2. The principle of pacing can be applied to sedentary behaviour where people need to take breaks. While not targeted at CP users or even for rehabilitation, *Breakaway* (Jafarinaimi et al. 2005) was an application deployed in the workplace to encourage sedentary workers to take frequent breaks. Sensors were positioned in people's chairs to detect how long they had been sitting. The application used an ambient display in the form of a small sculpture that slumped if the user ignored cues for taking breaks.

4.3.4 Frameworks for self-management technology for physical activity

We also reviewed existing technology frameworks for developing technology for physical rehabilitation. As reviewed earlier, most rehabilitation technologies act (directly) on the person to enable them to overcome barriers but they focus primarily on exercise and the physical aspects of measuring movement through situated and games approaches (Hersh & Johnson 2008). We found that existing frameworks mainly focus on the computational aspects of developing such systems giving details of software architectures to develop the technology (e.g. Egglestone et al. 2009, Saini et al. 2012). From the perspective of design factors, most of the systems focus on gamification and motivation (Saini et al. 2012). Charles & McDonough (2014) proposed a framework for participatory design of rehabilitation games based on gamification principles.

Other rehabilitation frameworks focus on either developing assistive technologies (e.g., Farrell et al. 2007) or exclusively on increasing physical capability (e.g., Egglestone et al. 2009), ignoring psychological factors. While assistive technologies work on improving functioning, they may do so by provision of support and substitution of capability to remove barriers rather than improving the capability to function (Hersh & Johnson 2008), which is not our aim in this thesis. Within affective computing, technology for automatic detection of pain and pain related behaviour is being developed (Olugbade et al., 2014, 2015; Aung et al., 2015; Walter et al. 2014). However, its use in supporting self-directed therapy is yet unclear.

4.4 Chapter Summary

Technologies for self-management support for people with CP are limited (Keogh et al. 2010; Rosser et al. 2009). In addition, the development of these technologies has been generally approached without an in-depth understanding of the condition or directly engaging with the stakeholders to understand user needs (Rosser et al., 2011). This has led to the development of technologies that disregard the psychological needs and barriers faced by people with CP in engaging in physical activity (Rosser et al., 2011). Indeed, most of the technologies reviewed did not report behaviour change outcomes. Only a few demonstrated a psychological approach but these mainly focused on relaxation rather than engagement in feared movement beyond walking. There is hence the need to better understand these needs and barriers to enable a more informed approach to the design of technology for physical rehabilitation.

Many applications for wellbeing or healthcare do target related areas such as increased physical activity and rehabilitation (e.g., Schönauer et al. Jansen-Kosterink et al. 2013, Tang et al., 2015). However, the design of rehabilitation applications for CP still relies on the presence of a clinician (physical or virtual) to address psychological needs. The design of applications for wellbeing in healthy populations (e.g., Consolvo et al. 2009, Lin et al. 2006) has been mainly informed by the theories discussed in Chapter 3. Therefore, they have a limited focus on emotional aspects and do not address the specific barriers to physical activity typical of CP. Their focus remains on building physical capabilities, while psychological capabilities are largely ignored.

Despite this, some of the mechanisms used by applications for healthy populations could be useful to the design of physical activity technology for people with CP. Some of the technologies discussed aimed to increase physical activity through setting goals, which was considered an important construct in the behaviour change literature. The visualisation of achievement through imagery and metaphors on the display of these applications also help with maintaining and encouraging further behaviour reinforcement (Consolvo et al. 2009). Sensors like pedometers and devices like mobile phones that are easily available, are not difficult to use, are accessible and portable. The sensors automatically upload exercise data that can be seen by the user in the form of feedback. Goal setting (Locke & Latham 2002) is supported in the interventions for CP, the behaviour change literature and the technology reviews as an important technique. An interesting aspect of movement games is the development of specific mini games targeted at the needs of the user (Alankus et al. 2010), which provide meaningful experiences for the user while focusing on increasing activity (Burke et al. 2009). However, there is no evidence of how such games transfer gains to real life where the environment is less

controlled and psychological barriers may be even stronger due to lack of control.

Building on the review reported in these last three chapters, the work reported in this thesis aims to address this gap: i.e., how to design technology that considers the psychological barriers in addition to the physical ones in CP to engage in self-directed physical rehabilitation. In doing so, we hope to contribute to physical rehabilitation in CP and beyond, such as many chronic conditions where psychological support is missing.

Chapter 5 Thesis approach and methodology

In the previous chapters, we highlighted the lack of technologies to address self-directed physical activity rehabilitation for CP. While technologies have been designed to encourage physical activity or support rehabilitation in CP and other conditions, none of them address the CP-specific psychological barriers to physical activity. Pain management therapies can address the barriers in the short-term when supported by physiotherapists but in the long-term, physical activity behaviours are not maintained. Further, these therapies cannot be directly translated into technological solutions as discussed in Chapter 2. Interventions based on behaviour change theories and frameworks presented in Chapter 3 have been used to design interventions to promote physical activity behaviour. However, they do not adequately address emotion, which is an important aspect of managing physical activity in CP. Hence, to design a user-centred technology for supporting physical activity in people with CP, it is important to build an understanding of the barriers, needs and strategies for physical activity from the perspective of people with CP with insights from experienced CP specialist physiotherapists.

In this chapter, we present the main research question for this thesis and research questions that motivated each study carried out. We used quantitative or qualitative methods in this thesis, depending on the research question being addressed. Qualitative studies were used to investigate the needs, barriers and strategies of people with CP and physiotherapists from technology for physical activity in CP, to conduct design studies, and to evaluate the developed technology in different settings such as the lab, hospital and home. An iterative design approach was adopted to cyclically develop a technology prototype, which was evaluated with users and clinicians and refined. Quantitative methods were used to test the technology prototype through controlled studies, a survey and using sensor data collected on the device.

Here, we present the research paradigm adopted for all the studies and our choices regarding methods, and study design. In hierarchical terms, the chapter starts with the research question for the thesis and a map of the studies conducted during the thesis to illustrate the contents and aims of each study, ethical considerations and recruitment of participants. We then focus on the qualitative methodology used for all the qualitative studies in this thesis, and theoretical influences on strategy for collection and analysis of the data for those studies.

5.1 Research question

The main research question that the studies in this thesis aim to address is:

How can interactive technology support people with CP in overcoming psychological barriers during self-directed physical rehabilitation?

As discussed in previous chapters, while many psychological and physical barriers affect adherence to a programme of physical activity in people with CP (see chapter 2), the literature is lacking on how people can overcome these barriers when self-managing their activity. To address our main research question, we carried out a set of incremental studies that build upon each other to respond to the following sub-questions (see Table 5-1):

- Part 1: Understanding: *What are the barriers to physical activity faced by people with chronic pain and what strategies are used to overcome them?*
- Part 2: Empowering: *How can sensing and feedback technology be used to address barriers and implement, extend and empower the identified strategies?*
- Part 3: Functioning: *How can interactive real-time feedback facilitate (i) self-directed physical activity (including functional activity) in the home and (ii) enable transfer of skills from exercise to physical activity?*

5.2 Types of participants and recruitment approach

Studies presented in this thesis were conducted with two types of participants: people with CP and pain specialist physiotherapists. Complementary perspectives from these two stakeholders enabled us to identify technology opportunities. Whereas people with CP can provide an account of their needs, of barriers and strategies used to meet them, they lack a formulation of their rehabilitation needs; physiotherapists with an understanding of CP can judge what type of activity is beneficial and achievable and link it to valued goals. An overall description of the recruitment policy for each group with inclusion and exclusion criteria is presented next in this section. Further details specific to studies in each of the three parts of the thesis are provided when describing the particular study, if different from the section below.

5.2.1 People with CP

Recruitment was primarily achieved by advertising details of the study online on the emo-pain project website (www.emo-pain.ac.uk), social media (twitter, facebook groups), pain websites (e.g., www.pain toolkit.co.uk, www.backcare.org.uk), pain forums visited by people with CP (e.g., www.painsupport.co.uk), through NHS pain management programmes and through word of mouth by participants, colleagues and friends. When potential participants contacted the

researcher in response to the study advertisement or information from other sources, they were sent an email explaining the purpose of the study. They were also asked for (i) a postal address to send further information about the project and consent forms and (ii) a telephone number. If they agreed to participate they were sent an invitation to take part, an information sheet and a consent form by post. Participants were given at least two days to consider participating in the study. Details taken over the phone were stored in accordance with the Data Protection Act.

Inclusion Criteria

- 18-70 years old
- Musculoskeletal low back CP

Exclusion Criteria

- People who do not speak/understand English

5.2.2 Physiotherapists

Physiotherapists were recruited from the pain management centre at the National Hospital of Neurology and Neurosurgery (NHNN) by sending emails with an information sheet to solicit interest in the studies. We recruited from this hospital because NHNN has a pain management centre with specialised pain management physiotherapists, most of who have Cognitive Behavioural Therapy (CBT) training. NHNN also runs a well renowned outpatient CBT-based pain management programme called COPE (Changing the Outcomes of Pain Experiences), led by psychologists and pain management physiotherapists.

Physiotherapists were given at least two days to consider participating in the study and were asked to sign a consent form before taking part in the study. We also obtained NHS ethics clearance to recruit participants with CP from this site.

Inclusion Criteria

- Working with people with CP

5.2.3 Ethical considerations

The studies had full ethical approval from the University College London Ethics Committee (Ethics numbers: Staff/1011/005, 5625/001) and the National Health Service (12/LO/1520, 12/0078) and participants gave informed consent (sample information sheets and consent forms for UCL ethics in the Appendix A. (A.1, A.2); sample information sheets and consent forms for NHS ethics in the Appendix A. (A.3, A.4). NHS ethics were used for recruiting from and conducting studies with participants recruited from the pain management centre at the hospital.

The process of applying for NHS ethical approval required us to plan our studies in detail and anticipate issues that could arise with participants within our study, and for this inputs from the pain-specialist psychologist on the supervisory team were very useful. For example, we included in the protocol that we would check rooms for studies to ensure disabled access and facilities on the same floor for convenience of participants. Further, to plan the duration of studies, we needed to consider how long people with CP could engage in physical activity before needing a break and overall. We also listed in the protocol options of offering breaks, stopping people from doing too much and offering assistance without patronising participants during the study. Without sufficient exposure to issues faced by people with CP at the early stages of this thesis, planning protocols for studies with such details would not be possible without access to specialist interdisciplinary support.

The preparation during the ethics process for planning situations that could arise with participants was useful to build rapport and trust with participants. Participants were informed that they could withdraw from the study at any time without penalty. They were also told that they could ask to review, clarify or ask for removal of their interview transcript at any time. They were made aware that the interviews/observation session/ focus group/ control study would be audio-/ video-recorded/ observed and that the data collected would be stored and disseminated in accordance with the Data Protection Act 1998. Participants were further informed that any data collected would be anonymised. We ensured anonymity by omitting participant names from the transcript, and instead using participant numbers or references.

5.2.4 The challenges of recruiting people with CP

Recruiting people with CP to participate in our research was often challenging. Some people felt that their pain and/ or fatigue made it difficult for them to commit to our studies, as they were unsure of how they would feel on the day of the study. Other factors such as anxiety about the research protocol, distrust of researchers, fear of stigma and disclosure have been cited in the literature as reasons for nonparticipation (Campbell et al. 2012) and were factors in our research as well.

Distrust about research was primarily encountered in recruitment that took place outside the NHS. As an example, we present one case where we recruited online and requested a message to be posted on a well-used CP forum by the moderator. Within minutes of the message being posted, comments were left on the thread that undermined the research and the researcher. For example, one person posted, *“I am wary too. You may mail to arrange a telephone interview, as my time windows are limited. I warn you that I don’t respect your opinions or in real terms I see*

your research as inappropriate". The people on the forum had access to the official website of the project and were aware that the research did not aim for a medical outcome of pain relief and that could have been one of the reasons for distrust. Some people questioned the benefit of the research to them, as they would not get any pain relief or other direct benefit or understanding of their condition from it. Such distrust has been highlighted in the literature as well: *"the pain experience itself and associated emotional distress can often increase participant burden and reduce motivation for participating in a research study when participants perceive a low likelihood for direct pain control benefits."* (Campbell et al. 2012). Two people from the forum volunteered to be interviewed and after their interviews they posted on the forum to reassure others about the authenticity of the research. One of the interviewees wrote to the researcher after the incident, *"I think you will have firmly got the impression that a lot of people who have a disability and chronic pain, are very despondent, cynical, angry, fed up and untrusting. The way I have been treated over the years by various government departments, their employees, the rules and regulations have made me the person I am today. A far cry from the person I was 23 years ago unfortunately. I loved life, [...] loved talking to people. If it were not for my youngest son's smiling face that 'appeared' in my mind one particular night when I was at an all time low, I might not be here today e-mailing you."*

Our strategy for studies was to ask participants what their preferred mode of contact was and inform them of how often we would contact them before the study to remind them. We would then send reminder emails/ texts or call them if preferred a few days before and then just the day before the appointment. Many people did not want to come to our Central London location, for studies that required this, because crowded trains, tube and buses could provoke anxiety. Ethically, we were not allowed to pay participants for participation but we offered to pay for travel and to hail and pay for a taxi if we felt that they were tired after the study or had a difficult journey and were reluctant to claim higher travel expenses.

There were many cases where participants cancelled and did not reschedule another appointment indicating that they had changed their mind about participating. Despite no obligation to explain, people explained that they were unable to attend because of onset of pain, difficulty in travelling, or other personal reasons. In one case, a participant repeatedly forgot her interview appointments; we visited her home on three different occasions at pre-arranged times and she was not home but every time she called us later to reschedule. She reported that sleep deprivation due to pain and pain medications made her feel *"confused"* and *"in a mental fog"*. Finally, her husband managed the appointment and we could interview her.

In this section, we highlighted some challenging aspects of recruiting participants with CP. Next, we discuss the methodological approach for studies in all three parts of this thesis.

5.3 Using a pragmatic approach

Methodological approaches in research are generally categorised into either quantitative or qualitative methodologies. Quantitative methodologies are typically positivist where hypotheses are tested through controlling conditions and objective measures. Qualitative methodologies are typically used to investigate more subjective phenomena; for example, to investigate beliefs, understanding and experiences, aligned with the interpretivist and constructivist paradigms. Limitations can be identified in each methodology. For example, quantitative studies are criticised for a lack of focus on context as variables are controlled, nullified and manipulated. While qualitative researchers value variation in context and uncertainty, they are criticised for their insights being too context-specific to their original study and for potential subjective biases. However, subjective biases also occur in study design and questions asked by quantitative researchers. Therefore, while, it is worth recognising the limitations of both approaches, it is also worth noting that there is no one right way to conduct research; both approaches are valid and should be used according to their suitability to the research question (Eisner, 2003). In this thesis, we took such a pragmatic approach and methods were used based on suitability to the research question. In addition to qualitative and quantitative studies, we also used iterative design for cyclical design, testing and evaluation of technology prototypes (in Chapter 9). Table 5-1 shows the studies carried out in all the parts of this thesis and the participant types for each type of study.

Our main approach in this thesis is qualitative and we have used qualitative studies in all three parts of the study. In the next section, we justify and provide an in-depth description of our use of qualitative methods as they are used throughout the thesis. However, the iterative design and quantitative analysis methods will be discussed in the corresponding chapters where they are used.

Table 5-1. Research methods and participant types. PT denotes physiotherapists; PCP denotes people with CP

Parts -> Data collection methods	Part 1: <i>Understanding</i>	Part 2: <i>Empowering</i>	Part 3: <i>Functioning</i>
Role-plays	PT		
Observation	PT + PCP		PCP
Interviews	PT, PCP	PCP	PCP
Focus groups	1. PT + PCP 2. PCP	PT	

Parts -> Data collection methods	Part 1: <i>Understanding</i>	Part 2: <i>Empowering</i>	Part 3: <i>Functioning</i>
Blogs and forums	PCP		
Diary studies			PCP
Iterative design		PT, PCP	PCP
Controlled study		PCP	PCP
Survey		PCP	
Behaviour analysis using device sensor data		PCP	PCP

5.3.1 The use of qualitative methods in this thesis

Qualitative methods can be employed (i) to investigate phenomena about which there is little information, (ii) to gain a new perspective on well explored phenomena, or (iii) to gain in-depth information that may be difficult to obtain/ convey through quantitative methods (Strauss & Corbin 1998). Qualitative methods are well used in HCI for user studies (Boardman & Sasse 2004), and data can be gathered using various methods such as interviews, diaries, observations, and focus groups. We used qualitative methods in this thesis to obtain rich descriptions and a deeper understanding of factors that affect uptake of physical activity in people with CP and how they overcome them (Berglund et al. 2006). To this end, we carried out a thematic analysis to identify, analyse and report patterns (themes) within qualitative data (Braun & Clarke, 2006).

For reliability and validity of qualitative studies several authors, for example, Patton et al. (2014), advocate the use of triangulation to strengthen a study by combining methods. Golafshani (2003) proposes triangulation through multiple methods of data collection and data analysis and that the methods chosen depend on the criterion of the research. There is no ‘fix for all researchers’ (Morse 1997: p604). Strauss and Corbin (1998) recommend obtaining multiple viewpoints through multiple data collection methods, such as interviews, observations and written reports to minimise bias. We used data and methods triangulation in the studies in this thesis by collecting data from different stakeholders (physiotherapists and people with CP) using multiple methods (role-plays, interviews, focus groups, observations, sensors, questionnaires, diaries) in various settings (control, hospital, pain management groups, home). This was done to obtain multiple perspectives on the understanding of the barriers to physical activity in people with CP and strategies used to overcome them and later to evaluate proposed frameworks and technology. Internal discussions with a clinical psychologist and physiotherapist within the team were used to disentangle conflicts and improve our

understanding during the study. This data was also enriched in Parts 2 and 3 of this thesis by the movement and breathing data of people sensed by the prototyped device.

5.3.2 Transcription and note making

To support a systematic approach to data analysis, the researcher transcribed all data². Transcription was non-verbatim, i.e., sounds such as “um,” “er,” were omitted; filler words and phrases such as “I mean,” “you know,” and false starts were removed. Silences and hesitation were not transcribed. Our focus was on improving readability but we did not summarise or paraphrase any part of the transcript.

All data sets were read and organised using (i) paper folders, (ii) Atlas.ti software, and (iii) research notebook. Memos and the research notebook were used to document thoughts and reflections as they changed through the project. Notes were made during observation studies and annotated through discussions with physiotherapists and internal discussions with clinical psychologist within the team. For all other studies, the researcher made notes immediately after the study to enable reflection on the immediate study and interactions with participant. These notes included contextual information and other important aspects such as setting of the study, participant reactions to questions, rapport with participant and on the study itself to improve/change questions or approach for subsequent studies.

- *Note:* In some cases, we found that after the recorder had been turned off after the study and people relaxed, they were likely to talk about their experiences and these insights were often very useful to the research. In these cases, notes immediately after the study were very helpful. We always asked permission from the participant for reporting such unrecorded data and were prepared to not use them if the person objected.

5.3.3 Data analysis methods

Thematic analysis was used as the analysis method for the qualitative studies in this thesis. This is a flexible approach that can be used across a variety of research questions and is useful in summarising the key features of large datasets in rich detail, and highlighting similarities and differences across the data. It also provides a way for researchers to clearly and transparently articulate the theoretical approach taken for a study analysis (Braun & Clarke 2006).

² The cued interviews with physiotherapists were transcribed another researcher, Annina Klapper, based on joint observations.

In this thesis, an inductive, latent and realist approach to thematic analysis was adopted. First, we used an inductive or ‘bottom-up’ approach indicating that themes are strongly data driven: this is similar to Interpretative Phenomenological Analysis (IPA) (Smith & Osborn 2015). Our approach was strongly driven by an interest in people’s personal perceptions and experiences of physical activity in CP rather than an objective account of the event (Murray & Chamberlain 1999). However, we are aware that the researcher’s conceptions have an influence on this process through a process of interpretative activity (Murray & Chamberlain 1999).

Second, we used a latent approach to the analysis to examine the underlying ideas, assumptions, and conceptualisations, going beyond the semantic (Braun & Clarke, 2006). During the analytic process a process of description to organise and summarise the data to illustrate patterns was carried out. Despite using an inductive approach, during the analysis we drew on relevant theory to make sense of the latent themes that emerged: *“the development of the themes themselves involves interpretative work, and the analysis that is produced is not just description, but is already theorised”* (Braun & Clarke 2006). Thus, this approach can be regarded as based on the realist paradigm which enables an emphasis on individual’s motivations, experience, and meaning (Braun & Clarke 2006). Taken as a whole, this enables a rich analysis of the person’s own experience and the ways in which they derive meaning from this experience, whilst acknowledging the influence of the researcher’s perspective.

We used a cyclical process of gathering and analysing data, i.e. we started an informal analysis with the first interview/ observation, leading to the next interview/ observation and analysis of that, and so on. This cyclical process allowed us to refine our approach and address theoretical gaps, increasing our confidence in the interpretation of our data. Notes were taken immediately after each study which included the researcher’s reflections on meeting the participant, context and content of the interview, any obvious contradictions within people’s own accounts, and other factors that made an impact on the researcher. This action gave context during the analysis, making the analysis richer and also emphasised the researcher’s impact on the study. As a measure to avoid bias, these impressions and the analysis were discussed with a physiotherapist and a psychologist on the supervisory team.

For the thematic analysis itself, Braun & Clarke (2006) provide a step-by-step process of six phases to structure the research. Although, these are logical phases of the research process, our research process did not map to such a linear sequence of tasks carried out but was a predictably *“nonlinear, recursive (iterative) process in which data collection, data analysis, and interpretation occur and influence each other”* (Willis 2007). We describe here the analysis process carried out by us, influenced by Braun and Clarke’s (2006) recommended process.

As a first step to analysis of qualitative data, intensive familiarisation with data was done by revisiting study notes and audio/ video recordings of the transcript. Parts of the transcripts were highlighted and annotated along with additional written notes reflective of the experiences and views of the participants and the researcher. Annotations were used to create initial content labels, which were translated into descriptive codes. As we ran more studies, we started comparing the codes generated to findings of initial studies and generalising codes. When coding transcripts from later studies, we started combining the codes and applying labels already in our data. We also constantly compared new codes with older ones and refined the codes throughout the study.

After an initial search for themes, we did iterative searching, reviewing, refining and naming of themes to refine the analysis and themes. We iteratively applied parts of the analysis to the whole dataset by applying the same labels to other parts of transcripts that referred to the same concept or idea. Analysis was refined through a cyclic process of revisiting and rereading data transcripts, renaming codes if needed (on identifying a more accurate description), merging codes (when existing codes referred to the same theme), splitting codes (when previously similar codes were found to differ) and recoding some data under a different code or unlinking data from a code (when the previously assigned code appeared to no longer fit appropriately). So, we needed to work with the whole dataset across studies. We also checked and rechecked codes for each participant and across the dataset for comparisons and contradictions to highlight them in the analysis or the report.

A qualitative descriptive summary of the findings was written up under the major themes identified. In the process of this thesis, such a report has been written multiple times at different stages of data collection for all the parts of the thesis. Writing up the themes was also an iterative process and a lot of new ideas were generated during the writing that modified the analysis and at times meant we needed to revisit the data.

5.3.4 Safeguards for avoiding data bias and introducing validity

Several authors (e.g., Silverman (2006); Strauss & Corbin (1998)) have demonstrated how qualitative research can incorporate measures that deal with validity and reliability. Several of the measures that were used in this thesis are to:

1. *Think comparatively* – We compared coding instances with one another across the dataset.
2. *Data triangulation* – (also discussed earlier in Section 5.3.2). We conducted studies using multiple methods in different contexts and with different stakeholders to get multiple viewpoints and perspectives.

3. *Periodically step back from the data* - We referred back to the data on a regular basis. Regularly revisiting the data and questioning assumptions we had made allowed us to gain confidence in our findings and to regularly feed any discrepancies we found into creating a revised theoretical picture.

4. *Respondent validation* – We periodically checked our interpretation of their responses with participants or asked for further clarifications.

5. *Discussion with other team members* – We often discussed our findings with other members of the team to provoke discussion and generate debate about our findings at different stages of the project.

5.3.5 Analysis tools

To support the coding process while analysing data, a mixed analysis technique was used. Coding was done using post its and paper notes, handwritten research memos and diagrams to make sense of relationships between codes and categories that were identified. This paper-based approach (Figure 5-1) was also useful for internal discussion with other team members. In addition, a qualitative research tool, Atlas.ti version 7.0, was used predominantly to organise the data. It was also used for some aspects of the research such as initial coding and probing differences between physiotherapists and people with CP. Examples of coding, code lists and memos created through Atlas.ti are presented in Appendix H. The software was also useful for revisiting and reviewing themes by creating ‘families’ of participants, splitting transcript documents among them and subsequently filtering of the display of data by family. The tool was also useful in examining nuances in the data through identification of co-occurring codes and different ways of sorting and filtering codes, quotes and data to identify relationships between them.



Finally, we provided a more detailed account of the qualitative research methods that were used for data collection and the overall procedure for analysis of such data in this thesis.

From here, the thesis is divided into parts 1, 2 and 3 based on the research questions. Part 1 will address the first research question through various qualitative studies including role-plays, observations, interviews, focus groups and analysis of online blogs and forum entries. Parts 2 and 3 will present the second and third study respectively that use a mix of qualitative and quantitative methods and iterative design studies.

Next, we present part 1 of this thesis to gain an understanding of the needs, barriers and strategies for support of physical activity in CP.

Part I

“Understanding”

Chapter 6: User Study Methods for Part 1.

Chapter 7: User Study Results: Barriers and needs to physical activity in CP.

Chapter 8: User Study Results: Strategies to facilitate physical activity CP.

Parts of the chapters in this part have been published as a paper in the Proceedings of CHI 2014:

*Singh, A., Klapper, A., Jia, J., Fidalgo, A., Tajadura-Jimenez, A., Kanakam, N., Bianchi-Berthouze, N., Williams, A. (2014). **Motivating People with Chronic Pain to do Physical Activity: Opportunities for Technology Design** in Proceedings of the 32nd ACM Conference on Human Factors in Computing Systems (ACM CHI 2014)*.*

*Roles of each author are listed overleaf

*Roles of each author.

Singh, A. designed, ran and analysed all qualitative studies (but cued-interviews). However, did co-analysed the cue-interviews too. She led the writing of the paper. The device in the paper was based on the findings from these qualitative studies.

Klapper, A. conducted the video-cued interviews.

Jia, J. ran pilot studies of the first prototype (not reported in this thesis) with Fidalgo, A. and Tajadura-Jimenez, A. when Singh, A. was on maternity leave.

Kanakam, N. was present at focus groups.

Bianchi-Berthouze, N. and Williams, A. are supervisors for this thesis and advised on the research as well as on writing the paper.

Chapter 6 Study methods for Part 1

In the previous chapter, we presented the overall methodology for the studies in this thesis. In this chapter, we describe the studies conducted in Part 1 of this thesis to address the first research question (see Table 6-1).

Table 6-1. Research question and studies for Part 1: “Understand needs, barriers and strategies”. The studies are presented in the order they were conducted. The role-plays were carried out first. Next the observations were carried out in parallel with the interviews and focus groups in that order. Finally, blogs and forum entries were analysed. S1 is used to refer to physiotherapists while S2 refers to people with CP in the figure.

UNDERSTANDING			
Research question	<i>What are the barriers to physical activity faced by people with chronic pain and what strategies are used to overcome them?</i>		
Study 1A: Role-plays with S1	Study 1B: Observations pain management sessions and group physical activity sessions with S1, S2		Study 1E: Analysis of blogs and forum entries by S2 related with physical activity
	Study 1C: Interviews with S1, S2	Study 1D: Focus groups with S1, S2	

This includes presenting the process of data gathering and method of analysis for the five studies conducted: observations, interviews, focus groups and analysis of blogs and forum entries. The results of all studies developed across the various methods of data collection conducted within part 1 are integrated and presented in the next chapter. While initially we planned to report each study separately, when writing up the analysis, we felt that incorporating data from across all the studies made the themes richer and stronger because of triangulation of findings from multiple methods.

As shown in Table 6-1, we first conducted a role-play study with two experienced physiotherapists. Findings from these initial role-plays and the literature were used to design further studies with people with CP and physiotherapists. Interviews with people with CP were used to get an in depth account of needs, barriers and strategies for physical activity and if they used any technology to support their physical activity, daily functioning or in their social lives. Interviews with physiotherapists were used to investigate methods of providing encouragement, addressing activity related pain beliefs and strategies to monitor progress or lack of it; they were also asked if they recommended any technology solutions to support patients. To get a more direct understanding of these needs, barriers and strategies in ecological settings, we planned observations of different types of sessions run by the pain management programme at the

National Hospital for Neurology and Neurosurgery (NHNN), followed by interviews with physiotherapists (cued by videos of the class) aimed at understanding the strategies physiotherapists use in motivating people with CP in therapeutic settings³ and also how patients react to the strategies while doing physical activity.

We conducted two focus groups: one for discussion between people with CP and one with physiotherapists and people with CP to further investigate needs and identify and clarify contrasting views, given the different roles these stakeholders have in pain management. Finally, an analysis was conducted of online blogs and forums related to physical activity in people with CP to get a further understanding in a natural setting where people discuss their problems and successes and share tips and solutions.

Details of the data gathering methods, the participants and recruitment process, and the collective data analysis methodology are discussed next. We present important details for analysis of each of the studies in a table within each study section. However, to avoid repetition, we do not repeat the material that is common to all the studies after presenting it first in Table 6-2. We refer back to this first table if the details of the subsequent tables are the same and only clarify differences if any. Analysis tools for all studies in this chapter are paper-based tools and Atlas.ti version 7.0 as mentioned in the previous chapter. Codes and themes for all studies will be reported in a story-like way in this thesis rather than reporting individual codes and number of quotations for each participant to convey the understanding developed.

6.1 Study A: Method of conducting role-play studies

Role-plays have been used in HCI, especially in a therapeutic context to “*generate new concepts, to test design ideas on potential users and as a technique for designers to help them ‘imagine better ... to empathise better’*” (Doherty et al. 2010: p245-246). We used role-plays to allow the physiotherapists to articulate what s/he considered the important parts of a therapeutic interaction (e.g. instructions, extent of correction or modelling of movement by the physiotherapist) and role-plays are considered an effective way to do this as they emulate a real session (Matthews et al. 2014). Role-plays are especially effective to elicit dynamics of the patient-therapist relation (Marks & Yardley 2004; Cassell & Symon 2004) including facial expressions, tone of voice and body language employed by therapists compared to other study methods.

³ The cued interviews were conducted by another researcher, Annina Klapper, based on joint observations. Transcripts were independently analysed as part of this thesis.

This section describes the method we used to conduct role-plays and how the role-plays helped us to start gaining an understanding and empathy for the CP condition and its lived experience. The role-plays also demonstrated how physiotherapists deal with the issues brought to their attention. Two role-play sessions were carried out with two experienced pain-specialist physiotherapists from the Pain Management Centre at the National Hospital for Neurology and Neurosurgery. The aims and details of the analysis of role-plays can be found in Table 6-2.

Table 6-2: Details of analysis of role-plays. * represents the information that is the same across all methods of data collection.

Study A: Role-plays		
Activity	Detail	
Aim	To gain familiarity with issues around activity and CP that are brought to the attention of the physiotherapist by people with CP, and some of the ways that experienced physiotherapists deal with them.	
Literature review	<ul style="list-style-type: none"> • CP and behaviour change literature reviewed before study * • Semi-structured script developed based on literature and understanding of pain management physiotherapy from other team members* 	
Sampling	Physiotherapists specialised in CP.	
Recording the session	<ul style="list-style-type: none"> • Video recording • Notes 	
Coding procedure	<ul style="list-style-type: none"> • Initial analysis in the same week as role-play study. • Coding was iterative and collated into themes through review. 	
Number of	Coders	Role-plays
	1	2 physiotherapists

During the role-play, physiotherapists were asked to simulate a one-to-one session with a person with CP. The guide for conducting the role-plays is in Appendix B. The role-plays were conducted with physiotherapists in their consulting rooms to get a realistic idea of how they interacted with patients in a usual setting and if they used any cues from their environment. The duration of each role-play was approximately 30 minutes and the sessions were videotaped with consent from the physiotherapists. Help was sought from another researcher (researcher 2) to conduct the role-plays. One of the researchers introduced, facilitated and video-recorded the session and took notes while researcher 2 took on the role of the patient in the first role-play. Two simulations were carried out. In the first case, the person with CP was played by a researcher whilst the physiotherapist played herself; in the second case, the first physiotherapist played the person with CP because she now knew what we were looking for after participating in the first role-play and was better informed to role-play a person with CP than the researchers.

A 15-25 minute follow up interview was conducted with the physiotherapists after each role-play where they were asked about particular situations and responses from the session.

6.1.1 Designing further studies

We used insights from role-plays to frame the interviews and focus group studies.

6.2 Study B: Method of conducting interviews

We conducted semi-structured interviews with people with CP and physiotherapists. A semi-structured interview script was used to ensure that we covered the same topics with each participant, while allowing the interviewer to explore interesting directions as they emerged (Rogers et al. 2011).

We were inspired by Petitmengin's (2006) interview techniques in designing the interview questions, such as regularly reformulating answers to stabilise attention, and focusing attention on singular rather than general events. Interview prompts and probes helped to remind participants of their experiences of physical activity and to elicit contextual information about how activity was performed, rather than simply what activity they were doing. Critical incident interview techniques (Butterfield 2005) were also used for retrospective self-report of incidents of personal significance with a focus on eliciting the beliefs, opinions, and suggestions that formed part of the incident itself. For example, instead of asking questions like, "*What kind of support do you want from a coach during an exercise session?*" we would ask, "*Can you think of any experience with a coach that you found motivating? What did he/she do that you liked?*" In doing so we aimed to get rich, in-depth and accurate descriptions of participant experiences. This process also allowed us to develop an understanding of contextual factors determining people's activities and routines. The interview guide evolved during the study and we refined questions further according to emerging themes. The specific details of interviews with people with CP and physiotherapists are discussed in the next sections separately.

6.2.1 Interviews with people with CP

Sixteen people with CP (10 women and 6 men) ranging in age from 19 to 74 years participated in our interview study. All participants had CP (since 4 to 38 years). Details of participants can be found in Table 6-3. Informed consent was obtained from all participants. The recruitment and consent procedure was the same as that explained in the previous chapter. To make the interview process as easy for people as possible, we did telephone interviews wherever convenient because people with CP usually find travelling difficult, and we could reach more participants if we did not limit the recruitment geographically. Face to face interviews were

conducted at places convenient to the interviewee. All data were anonymised and no real names were used in the transcriptions.

Table 6-3. Details of people with CP interviewed

PCPI#	Age	Sex	Years CP	Physiotherapy / PMP
PCPI1	50	F	30	Ongoing
PCPI2	51	M	23	X2 (22 y ago)
PCPI3	28	F	17	No PMP; Physiotherapy: 10-15 years ago
PCPI4	36	M	4	No PMP
PCPI5	56	F	26	Yes (several)
PCPI6	46	F	38	1 week ago
PCPI7	57	M	4	No PMP
PCPI8	58	M	20	18 years ago
PCPI9	31	F	16	6-8 months ago
PCPI10	53	M	15	AS treatment
PCPI11	52	F	5	6 months ago
PCPI12	48	F	5	Y (can't remember)
PCPI13	19	M	5	N (seen consultant)
PCPI14	37	F	18	2 years ago
PCPI15	25	F	14	No PMP
PCPI16	74	F	37	No PMP

The aim of the semi-structured interviews is presented in Table 6-4 along with other information about the analysis. We asked people with CP about their experiences with self-management of everyday physical activity, household activities, exercise routines, and barriers to activities. We also asked them about strategies they use to maintain and increase physical activity or to meet physical demands despite barriers (see Appendix C. for semi-structured interview topics).

Table 6-4. Details of conducting interview studies with people with CP

Study B-1: Interviews with people with CP	
Activity	Detail
Aim	To investigate barriers to physical activity in people with CP and strategies used by people to overcome the barriers.
Literature review	<i>Same as</i> Table 6-2. In addition, findings from role-play influenced design of study.

Study B-1: Interviews with people with CP		
Activity	Detail	
Sampling	Interviewees were predominantly sampled opportunistically; we recruited from pain management groups; in some cases people were volunteers (self-selected) who responded to calls to participate in the study that were posted on the project website or social media.	
Interview procedure	Semi-structured interviews lasting 30-45 minutes. Guiding topics can be found in Appendix C. Topics were probed opportunistically.	
Recording	<ul style="list-style-type: none"> • Audio recording using voice recorder in face-to-face interviews. • Skype and Call-Recorder used to record telephone interviews. 	
Coding procedure	<ul style="list-style-type: none"> • Informal analysis was done between interviews. • All interviews were transcribed and coded by the researcher. • After 6 interviews, transcriptions were re-coded to reduce the codes. Analysis style was loose, in that codes were not mutually exclusive. Coding and linking of codes were done simultaneously. • Memos and notes were used throughout the analysis. 	
Number of	Coders	Interviews
	1	16

6.2.2 Interviews with physiotherapists

Semi-structured interviews were conducted with three pain management specialist physiotherapists (see Table 6-5), with pain management experience of between 6-10 years. The aim of the interviews and other details of the study are in Table 6-6.

Table 6-5. Details of pain specialist physiotherapists interviewed

PT#	Years working with people with CP	Intervention
PTI1	8	CBT
PTI2	10	CBT, Mindfulness training
PT3	6	CBT

Table 6-6. Details of conducting interview studies with physiotherapists

Study B-2: Interviews with physiotherapists	
Activity	Detail
Aim	To investigate how physiotherapists, specialised in pain rehabilitation, support and motivate people with CP to build physical activity.
Literature review	<i>Same as</i> Table 6-2. In addition, findings from role-play influenced design of study.

Study B-2: Interviews with physiotherapists		
Activity	Detail	
Sampling	Pain specialist physiotherapists were recruited for the study.	
Interview procedure	Semi-structured interviews lasting 45-60 minutes. The interview script is in Appendix C. Topics were probed opportunistically.	
Recording tools	<ul style="list-style-type: none"> • Audio recording using voice recorder in face-to-face interviews. • Skype and Call-Recorder used to record telephone interviews. 	
Coding procedure	<ul style="list-style-type: none"> • Informal analysis took place between interviews. • All interviews were transcribed and coded. • Analysis style was loose, in that codes were not mutually exclusive. • Coding and linking of codes were done simultaneously. 	
Number of	Coders	Interviews
	1	3

6.3 Study C: Method of conducting observations

We observed group sessions with people with CP: these included general group physical activity sessions conducted by pain management physiotherapists, pain management information sessions run by physiotherapists and psychologists, and a pain management rehabilitation session run by a physiotherapist. The aims of the observation sessions and details of how they were conducted, analysed and reported are in Table 6-7. Details of the observed sessions are in Table 6-8.

Table 6-7: Details of Observation studies

Study C: Observations		
Activity	Details	
Aim	To elicit from physiotherapists a range of ways of enhancing motivation and giving CP and activity related information and instruction, given individual differences and varying levels of ability among patients.	
Literature review	<i>Same as</i> Table 6-2. In addition, findings from role-play influenced design of study.	
Recording	Notes of observations in notebook <ul style="list-style-type: none"> • Audio and video recording in some sessions. 	
Coding procedure	<ul style="list-style-type: none"> • Informal analysis took place between sessions. • Analysis style was loose, in that codes were not mutually exclusive. • Coding and linking of codes were done simultaneously. 	
Number of	Coders	Observations
	1	9

Table 6-8: Details of observed sessions

No.	Session type	Patient type	Group size	Exercise type	Duration
1	a. Pain management introduction	Back pain	n=6	Group stretches Education	1 day
	b. Pain management introduction	Joint-Hypermobility	n=9	Group stretches Education	1 day
2	a. Group exercise: general drop-in session (6 sessions observed)	Mixed CP patients	n=12	Group stretches Gym	60 mins
	b. Group exercise: rehabilitation session for specific condition.	3 month post operation check with bone fusion, persistent pain	n=3	Education Gym	60 mins

The pain management introduction sessions, 1a and 1b in Table 6-8 are discussed together in the next section as they were run in a similar manner. Also, the group exercise rehabilitation session and the general group exercise session (2a and 2b in Table 6-8) were run in a similar manner and both settings are described together in Section 6.3.2.

6.3.1 Pain management introduction session

A pain management programme introduction was observed to understand how people with CP were given information and advice about managing pain. This session, conducted by psychologists and physiotherapists, included information about pain management and physical exercises. Interactive activities and outings (e.g. coffee shop, library) were carried out during the session to practice managing pain in everyday situations and identify potential problems.

Physiotherapists introduced the study and provided information sheets to patients in a previous session so that people had time to decide if they wanted to participate. Prior to the session on the day of the study, we reintroduced the study and invited questions or concerns about participation. We told patients that we would leave at any point during the session if any of them changed their minds about the study. To avoid disturbing patients in this session, we sat at the back of the room, in the row of seats behind the patients to observe the sessions. We did not record these sessions and only took notes. Later in the session, we accompanied participants on outings (once to the British Museum and another to a local bookshop), where we observed the physiotherapist prompting people about strategies for situations in which they needed to rest/take a break, anticipated problems and strategies to mitigate their anxieties in busy public

places. An excerpt of a table interactively drawn on a white board by a physiotherapist with inputs from people with CP after the outing is presented in Table 6-9. Such scenarios from people's everyday lives were used to give pain management information and advice and also to propose self-management strategies including physical activity.

Table 6-9. Behaviour experiments in pain management introduction

Situation	Prediction	Experiment	Outcome	Learning points
Walk to bookshop	Will be in agony	Focus on taking breaks and walking at easy pace.	Felt more manageable than expected	-Set manageable targets -Enjoy journey rather than focus on destination.
Queuing for tea	Increased pain	Find place to sit or lean	No pain increase	Other people are not that interested so no need to feel self-conscious or embarrassed about taking breaks.

6.3.2 Drop-in group activity session

Drop-in sessions were physiotherapist-led sessions of physical activity that ran every week at the pain management centre and people with CP registered at the clinic were invited to attend. Session participants were at different levels of abilities and pain management experience. These sessions were useful to elicit from physiotherapists a range of ways of enhancing motivation and addressing emotional barriers to activity given individual differences among patients' physical and psychological capabilities

Sessions were generally carried out in a big room with two physiotherapists present. One of the physiotherapists directed, instructed and modelled the activity from the front of the room. The wall behind the physiotherapist and faced by the participants had a mirror. Chairs were lined up against the opposite wall for people to sit if needed. The second physiotherapist sat to one side of the room to observe the session, to demonstrate exercise modifications for people seated in chairs and to assist individuals discreetly if they were in distress or asked for help.

We asked physiotherapists to introduce the study and provide information sheets to patients in a previous session so that people had time to decide if they wanted to participate. Prior to the session on the day of the study, we reintroduced the study and invited questions or concerns about participation. We emphasised that we would leave at any point during the session if any patient changed his/her minds about the study. The researcher made notes about the session. Three of the six sessions were also video-recorded with verbal consent from participants and written consent from the physiotherapist. Video recordings are an effective method to capture

communication and socio-affective behaviours by physiotherapists in a therapeutic scenario (Talvitie 2006). Two cameras were used during the group sessions: one capturing the physiotherapists' facial expressions and the other capturing the body of the physiotherapist. Physiotherapists also wore a small microphone to enable audio recording.

After the group session, people stayed in the gym for another 30 minutes. They used the gym equipment while the physiotherapists walked around the room giving people information on using the equipment, and pain management related advice (e.g. planning their day, pacing, starting with stretches). The gym was also a social space where people could talk to each other and exchange tips and difficulties.

6.4 Study D: Method of conducting focus groups

Focus groups focus on generating from the communication between a group of research participants. Differently from group interviews, focus groups explicitly capitalise on group interaction as an integral part of the method. Rather than the researcher eliciting a response to each question, participants interact, converse, and question each other's perspectives and experiences (Kitzinger 2005). The method is particularly used to explore people's knowledge and experiences and their interactions. We conducted two focus groups, each with different aims and in different settings. The details of the focus group studies are in Table 6-10

Table 6-10. Details of focus group studies with people with CP and physiotherapist

Study D: Focus groups	
Activity	Details
Aim	To investigate barriers to physical activity in people with CP and strategies used by people to overcome the barriers.
Literature review	<i>Same as Table 6-2.</i> In addition, role-play findings influenced study design.
Sampling	The first focus group was held with people with CP and physiotherapists who had previously been interviewed; the second focus group was held at a pain management group.
Focus group procedure	The focus group interview guide was semi-structured; Guiding topics can be found in Appendix D. Topics were probed opportunistically. A movement game video was shown to elicit concerns, views and ideas for technology and generate discussion.
Recording	<ul style="list-style-type: none"> • Video and audio recorded • Observation notes taken by note-taker
Coding procedure	<ul style="list-style-type: none"> • Focus groups were transcribed and coded. • Analysis style was loose, in that codes were not mutually exclusive; initial coding and linking of codes done simultaneously. • Memos and notes were used throughout the analysis.

Study D: Focus groups		
Activity	Details	
Number of	Coders	Focus groups
	1	2

6.4.1 Focus group 1

The first focus group was held after 10 interviews with people with CP and 3 interviews with physiotherapists had already been conducted. A mix of people with CP and physiotherapists were invited to the focus group. Since the findings from the observations and interview studies revealed interesting contrasts and synergies between the physiotherapists and people with CP, a decision was made to involve both in the focus group for discussion. Such involvement of different stakeholders is not typical for focus groups (Kitzinger 2005). Homogeneous groups are preferred as people are likely to feel safer discussing sensitive issues with other people with a similar life experience and problems, thus permitting more disclosure and a more open discussion (Kitzinger 2005). On the contrary, a heterogeneous group involving healthcare provider and patients may have an uneven balance of power, which could deter the “*less powerful*” – the people with CP in this case - from speaking, particularly to contradict the more dominant members of the group. However, having interviewed both groups, we mitigated such limitations by inviting people with CP who were expert patients; i.e. they did not consider themselves only as patients but also as advocates for patients, and they were used to working in partnership with healthcare providers. We invited physiotherapists with whom they had not interacted previously. We tried to keep the group balanced by inviting two physiotherapists and three people with CP. Unfortunately, on the day some participants were unable to attend because of unforeseen circumstances and we had to conduct the focus group with one physiotherapist and two people with CP. Details of the people with CP and physiotherapist who attended the focus group are in Table 6-11 and Table 6-12.

Table 6-11: Details of participants with in focus group 1

FG1P#	Age	Sex	Years with CP	PMP
1	50	F	30	Y
2	58	M	20	1996

Table 6-12: Details of physiotherapist in focus group 1

FG1PT#	Years working with people with CP	Intervention
1	10	CBT, Mindfulness

Planning and setup

We invited participants to participate in the study by email. They were sent a brief outline of the study with the invitation. If they agreed to participate, we sent them an information sheet and a consent form. We ensured that the room booked for the study was easily accessible with natural light and equipped with mats and cushions for comfort. Tea, coffee and other refreshments were available from the beginning of the session and lunch was also provided. As shown in Figure 6-1, the room was set up with a flip chart and participants were provided with pens and post it notes to write topics or notes of things they found most interesting to be discussed before closing the session. Figure 6-1 shows the setup of the room for the focus group.

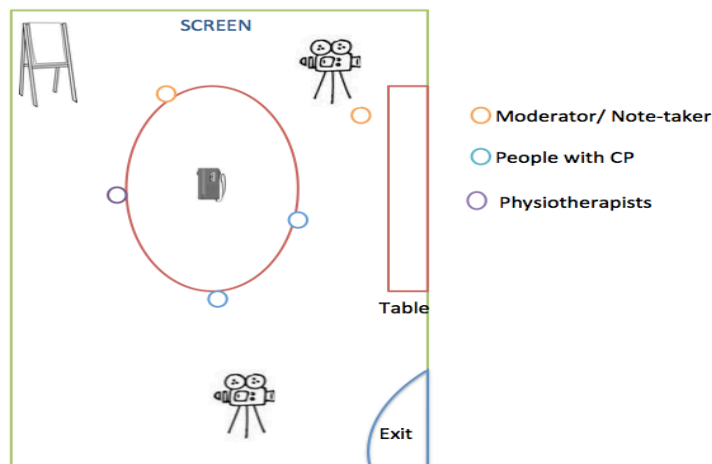


Figure 6-1. Setup of the room for focus group 1 showing the placement of the cameras, the flipchart and other equipment in the room. It also shows the position of the participants and moderator

Running the session

The focus group was moderated by the author while another researcher acted as note-taker during these sessions and monitored cameras. The focus group was conducted using a semi-structured interview script for 120 minutes with a scheduled 30-minute break for lunch but participants preferred to continue through lunch. Participants were encouraged to move around or adopt comfortable positions (e.g., lying down, leaning against the window) during the discussion. Details of the focus group are provided in Table 6-10 and the focus group information sheets, consent forms and script are attached in Appendix D.

The focus group was conducted with a mixed style. Initial introductions and discussions were relaxed and conversational to ease people into discussion and build rapport. Later questions were more interventionist: probing, urging debate to continue beyond the stage it might otherwise have ended and encouraging participants to discuss the inconsistencies and contradictions. Disagreements were used to clarify individual perspectives and views.

Participants were also shown a demonstration of existing relevant technology (such as videos of the Kinect or Wii) to generate discussion.

6.4.2 Focus group 2

The second focus group was held at a monthly patient support group meeting. 20 people with CP (13 women, 7 men) in the age range of 22-63 years participated in the group. Conducting the focus group at the support group meeting was a familiar and convenient setting for people to discuss their views, as they attended the group every month and knew others at the group. Details of people who participated in the focus group are in Table 6-13.

Table 6-13: Details of CP participants of focus group 2

FG2P#	Age	Sex	Years with CP	PMP
1	32	F	3	Y
2	60	F	4	Y
3	57	M	10+	2011-12
4	47	F	18	Y
5	51	F	10+	2011
6	42	F	16	Y
7	52	M	12	2010
8	58	F	24	Y
9	45	M	16m	2011,12
10	27	M	12	2011, 12
11	25	F	11+	2012
12	53	F	6	2012
13	50	M	14	Y
14	63	M	30+	2000, 2010
15	50	F	4	2010-12
16	48	F	4	2012
17	22	F	3.5	2011,12
18	60	F	11	Y
19	58	M	-	Y 2001
20	52	F	8	Y

Planning and setup

We contacted the group coordinator for organisation of the focus group. We sent her all the information sheets, consent forms and details about the focus group study to be distributed to members at an earlier meeting, so that people had time to think about participation. On the day of the study, before starting the session, we explained its purpose and took consent. Refreshments were provided as part of their monthly arrangements for the group.

The setup of the room for the focus group is shown in Figure 6-2. Two video cameras were set up towards the back of the room and two audio recorders were placed on the tables in the middle of the room to ensure that everything was recorded since the room and number of participants were big. Pens and post-it notes were provided to participants to make notes of aspects they found interesting or wanted to discuss before closing the session.

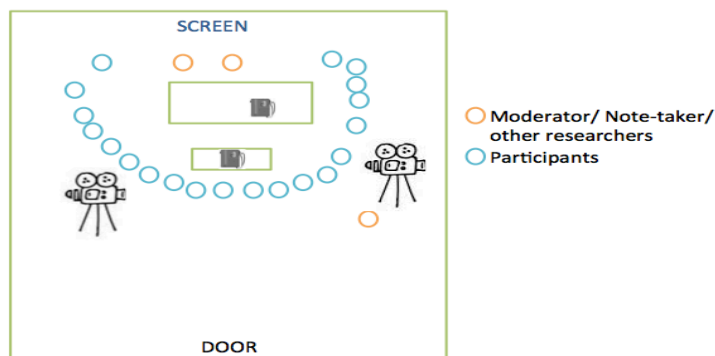


Figure 6-2. Setup of the room for focus group 2 showing the placement of the cameras and other equipment in the room. It also shows the position of the participants and moderator/ note takers

Running the session

The focus group was led by the author who acted as moderator. 2 researchers acted as note-takers during the session and they also monitored the group and cameras. The focus group was conducted using a semi-structured interview script. The focus group script is attached in Appendix D. The focus group lasted 80 minutes. Participants were encouraged to move around or adopt comfortable positions (e.g. lying down, leaning against the window) during the discussion. With consent from participants, these focus group sessions were audio- and video-recorded.

The moderator started by going round the table asking people to introduce themselves: people with CP told the group about their pain and pain management experience.

6.5 Study E: Method of analysing blogs and forum entries

As for many other health conditions, dedicated online support groups exist for CP. A blog (abbreviated from weblog) is an online personal journal available to the public, used by people

to share parts of their lives. The informality and conversational aspect of blogs can give researchers public access to the writer's thoughts and feelings. They provide insights into everyday experiences that can be very informative and allows researchers to consider events and experiences irrespective of location or time. Many people have blogs dedicated to their everyday experience of CP while others write about CP among other things. Some blogs invite guest bloggers to share their CP experiences. Discussion forums were also analysed to see concerns of people with CP about physical activity that they share online with other people with CP and tips and strategies that they give about physical activity despite pain.

For people with CP, as other chronic illnesses, blogs provide a medium to express themselves to an audience of “*sometimes total strangers, sometimes their best friends and colleagues and family members*” (Nardi, Schiano et al. 2004, 44). While talking about the issue is a motivator for using the medium but blogs and forums also provide a way to get support and understanding from others (Nardi, Schiano et al. 2004).

We conducted analysis of blogs and forum entries to see how our results compared to what people were discussing online with others as the barriers they faced to doing physical activity and any strategies. We were also interested in support offered on these platforms, such as tips and strategies about physical activity. Online blogs and discussion forums contributed a rich dataset in a naturalistic setting that was not guided by the researcher. Table 6-14 has details of the aims of the study and the process of identification and analysis of this dataset.

Table 6-14. Details of analysis of blog and forum entries

Study E: Blogs and forums		
Activity	Details	
Aim	To investigate barriers to physical activity in people with CP and strategies used by people to overcome the barriers.	
Literature review	<i>Same as Table 6-2.</i>	
Sampling	7 publicly available blogs and 18 publicly available forum entries.	
Coding procedure	<ul style="list-style-type: none"> • Analysis style was loose, in that codes were not mutually exclusive; initial coding and linking of codes done simultaneously. • Memos and notes were used throughout the analysis. 	
Number of	Coders	Blogs and forums
	1	25

Advantages of using data from blogs and forums include convenience and ease of access. They are less time and resource demanding and often pre-categorised by the blogger according to

keyword or topic. Personal blogs typically provide candid reflections and rich data, away from the influence of or interference from the researcher. It therefore avoids influences such as the Hawthorne effect (Hartley, 2001), which may cause participants to emphasise aspects of their experiences which they think will please the researcher. However, blogs are also subject to biases due to their need for endorsement by their readers through comments or visit counters. Turgeon refers to blogging as a need for “feeling heard, and sometimes understood” (2004). This need to be endorsed indicates that bloggers are unlikely to alienate their readers or audience and may embellish their accounts or bias their topics to interest their audience. Therefore, blogs may contain genuine experiences as well as biased content which needs to be considered to use blogs for research. Further bias in the data sample available through blogs may be because typically blogging is done by people who like writing and on a computerised medium. Therefore, people who are not technologically savvy may not be represented in the data sampled.

25 blogs and forum entries⁴ on physical activity by people with CP on websites and social groups related to CP support were analysed to supplement data from the interviews. The search terms used were ‘CP’ and ‘physical activity’ on Google to identify blogs. Blogs that did not focus on barriers or strategies related to physical activity for people with CP were discarded. For forum entries we searched for ‘physical activity’ on popular CP discussion forums.

Forum entries were anonymised and all personal data was removed before analysis. Only publicly available blogs and forum entries with unrestricted access were used for this research. In addition to the usual approach to anonymising personal data (e.g., removing names, addresses, etc.), additional data scrubbing was done because removing traditional information is no longer sufficient to ensure complete anonymity (Schwartz and Solove, 2011). This was done by:

- Changing usernames as people may have the same identifiers on different online sites that may link back to their identity. Usernames were replaced with identifiers such as BCP# (Blogger with CP followed by a number) or FEx#CP#(Forum Exchange number followed by person with CP identifier).
- Participant online signatures and identifiable graphics or pictures were removed.
- Identity clues that could be embedded in entries such as email addresses or usernames were removed.

⁴ Since blogs and URLs can be identifiable, for ethical reasons we will not provide URLs in this thesis. However, we can provide URLs for examination purposes on request.

No blogs or forum entries from websites or forums that required registration or membership for viewing were used.

6.6 Chapter Summary

In this chapter, we presented the research methods for studies conducted for addressing the first research question in this thesis (Part 1). We discussed the methods for each of the studies of Part 1 including role-plays, interviews, observations, focus groups, and analysis of blogs and forum entries.

In the next two chapters, we will present the findings from all these studies together. First (Chapter 7) we will present the needs and barriers that emerged and how they interfere with physical activity. Second (Chapter 8) we will present the strategies that were identified and that help to overcome the barriers and not only to engage with physical activity but also to develop the skills to self-direct it.

Chapter 7 User study findings: barriers and needs for physical activity in CP

In the previous chapter, we presented the study methods for all the user studies conducted to address the first research question, i.e. to understand the barriers to and strategies for physical activity support in people with CP. In this chapter, we present the results of the thematic analysis conducted on the gathered data. The method of conducting thematic analysis for this thesis was presented in Chapter 5.

We have integrated findings across all the studies conducted for presentation, as we found this enriched the description of the data and minimised repetition. By triangulating data from all the methods, the latent themes that emerged were stronger. Five overarching themes were identified: (i) conceptualizing pain management as a journey, (ii) affective barriers that interfere with physical activity, (iii) strategies for relocating control for physical activity in oneself, (iv) strategies to explore, build and maintain activity for everyday functioning, and (v) (re)building social alliances. The themes and their descriptions are listed in Table 7-1.

Table 7-1. Key integrated themes from qualitative findings

Theme	Description
1. Conceptualizing pain management as a journey	There are different barriers, strategies and needs for activity based on the stage of the pain management journey and personal experience of managing pain of the person with CP.
2. Affective barriers that interfere with physical activity	We identified affective barriers to physical activity based on our studies with people with CP and physiotherapists.
3. Strategies for relocating control for physical activity in oneself	We identified strategies used by physiotherapists in pain management programmes identified by people with CP and physiotherapists that help to build confidence in self-directing physical activity.
4. Strategies to explore, build and maintain activity	People with CP and physiotherapists identified strategies for self-management and ways to apply learnt strategies.
5. (Re)building social alliances	Social needs and strategies were identified for doing physical activity with others or with their support.

Table 7-2 highlights how each study described in the previous chapter contributed to the emergence and understanding of those themes.

Table 7-2: List of themes and how each study contributed to their emergence. Interviews and focus group study are grouped in a single column as they had a similar aim and contribution.

Research outcomes and findings	Role-plays	Interviews and focus groups	Observations and video-cued interviews	Blogs and forums
Aims of the study ->	To gain familiarity with issues faced by people with CP during physical activity and how physiotherapists deal with them.	To investigate barriers to physical activity in people with CP and strategies used to overcome those barriers;	To elicit from physiotherapists, a range of ways of enhancing motivation and giving instruction	To investigate barriers to physical activity in people with CP and strategies used to overcome the barriers.
Themes	What emerged from each study:			
Conceptualising pain management as a journey (Section 7.1)		<ul style="list-style-type: none"> • Emergence of psychological, physical and self-management journeys (not just physical as previously assumed by technology designers) • Person's needs change at different stages of journey. 		<ul style="list-style-type: none"> • Peer support emerged as a key factor in managing pain. • Previous experience of managing pain established trust and credibility.
Affective barriers that interfere with physical activity (Section 7.2)	<ul style="list-style-type: none"> • Initial understanding of issues faced by people with CP during physical activity • This informed initial study design. • Also provided training and development of empathy for CP condition (Chapter 13) 	<ul style="list-style-type: none"> • Deeper understanding of how each affective state interferes with pain management and physical rehabilitation. 		<ul style="list-style-type: none"> • Identification of affective factors in a wider population group (not just London based).
Strategies for relocating control for physical activity in oneself (Section 8.1)	<ul style="list-style-type: none"> • Introduction to physiotherapist's methods to maximise adherence. • Importance of increasing capability and awareness rather than correcting 	<ul style="list-style-type: none"> • Initial description of strategies to support body awareness, and to facilitate anxiety reduction and transfer of skills. • Role of physiotherapists 	<ul style="list-style-type: none"> • A practical understanding of how strategies are used and applied and the rationale. • Physiotherapists' verbal and non-verbal behaviours while applying strategies. • More strategies in 	<ul style="list-style-type: none"> • Understanding of when people feel unsupported in doing physical activity. • Identification of peoples' developed (rather than

Research outcomes and findings	Role-plays	Interviews and focus groups	Observations and video-cued interviews	Blogs and forums
	movement to achieve a perfect standard (different from typical rehabilitation approaches for technology design)	emerged to facilitate skills transfer rather than direct and supervise activity and control progress.	addition to the interviews. <ul style="list-style-type: none"> Video-cued interviews provided insight into strategies physiotherapists habitually used in CP rehabilitation. 	physiotherapists-thought) strategies.
Strategies to explore, build and maintain activity for everyday functioning (Section 8.2)		<ul style="list-style-type: none"> Importance of everyday functioning as main source of exercise rather than clinically-modelled situated exercise sessions. Importance of habits and routines, strategies for building habits/ routines. Personal motivation strategies. 	<ul style="list-style-type: none"> Importance of identifying and applying pain management strategies through demanding real life situations (e.g., pacing strategy while queuing in coffee shop). 	<ul style="list-style-type: none"> More instances of everyday functioning, habits, routines and motivation strategies emerged.
(Re)building social alliances		<ul style="list-style-type: none"> Strategies for being active with others (friends, family and others with CP) 	<ul style="list-style-type: none"> Emergence of pain management programmes role to provide opportunities for peer support. 	<ul style="list-style-type: none"> Sharing of people's developed strategies for progress and for social participation.

Next, each theme is discussed in relation to how it can inform the design of technology for physical rehabilitation in CP. Themes 1 and 2 will be discussed in this chapter. They provide an understanding of the barriers to physical activity and the progress necessary to facilitate self-management of physical activity. The strategies (Themes 3-5) are presented in the next chapter.

To differentiate between participant quotes from different methods of data collection, we use the following notation: P# denotes interviewed participants with CP, PT# denotes interviewed physiotherapists, PTRP# denotes role-play physiotherapists, PFG# denotes focus group participants, PTO# denotes observed physiotherapists, PO# denotes observed people with CP, OFB# denotes entries from online forums/ blogs.

7.1 Conceptualising pain management as a journey

Through all the studies, people with CP and physiotherapists referred, directly or indirectly, to the journey of pain management. While as a metaphor *journey* can imply heading towards an end, in our studies it was used to indicate engagement with pain management, managing expectations of change and focusing on improving daily function despite pain rather than on a cure. Since our focus was on managing physical activity not wider pain management, we used the *journey* to refer to needs, barriers and strategies for self-management of physical activity.

The concept of the *journey* (see Figure 7-1) helps to emphasise the differences in targets and more importantly methods used for rehabilitation according to the current state of the person with pain. At the beginning of the journey, everyday activities could be a challenge and trigger feelings of anxiety and guilt. PFG2 explained, *“Most people in the beginning are going to struggle with just activities of daily living and that’s probably the thing that’s causing the most anxiety: either an inability to look after themselves or look after other people in their family”*

Physiotherapists reported that in the beginning, they provided information and strategies such as building self-awareness of people’s bodies and its capabilities. Some participants felt that measuring progress in the early phases of the journey could be motivating for them as evidence of progress even if it was slow. P1 explained, *“When I first did a functional restoration program we used to keep a tally. We used to do three reps (repetitions) the 1st day and then the next day if you could do 4 reps that was great, and then 5 and they encouraged us to keep a chart of our progress so there was a tangible demonstration of progress which is very empowering.”*

In the latter phases, people with CP need to maintain their activity, and introduce variation but find that some of the pain management principles and skills that they had learnt earlier were now *“second nature”* (P16). At the beginning of the journey, people felt they needed more support to encourage them to do activity and to make them aware of their activity levels to avoid overdoing, not just during exercise but throughout the day. PFG2 said, *“It might be one of those useful reminders. When you say, ‘Well done, you’re here and you’re moving [...], now remember that you have spent twenty minutes exercising and you need to think about that as part of your activity during the day.’ When somebody’s five years down the line, we don’t need those reminders, but initially you need those reminders because you don’t have this concept, this whole life concept, which is what it is.”* The journey is hence not just about meaningful emotional and physical resources during exercise, but it is about learning to manage those resources during the full day.

The pain management journey can be envisaged as having multiple parallel journeys within it (see Figure 7-1), referring to different activities and emotional barriers that people may be working on and people can be in different phases in each of these journeys.

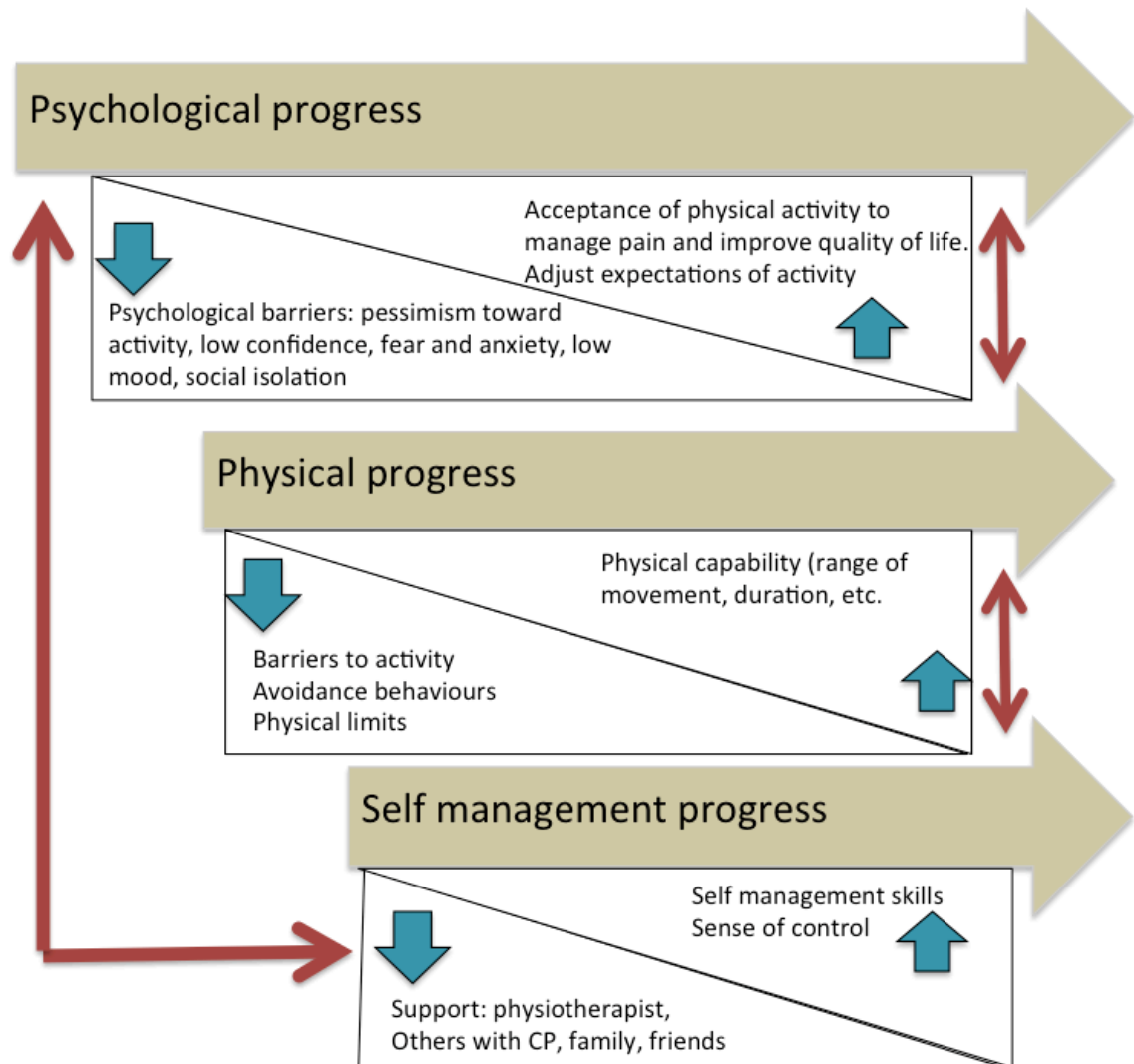


Figure 7-1: The pain management journey: To start the journey people need to accept that they need to manage their pain and activity rather than search for a cure. Three parallel journeys emerged denoting psychological progress, physical progress and self-management progress. The red arrows show that the journeys interact with each other. The green arrows within each journey show factors increasing and decreasing as the pain management journey progresses.

As people go along the pain management journey to manage their activity, barriers reduce as they learn to identify and address them. At the same time, they learn to increase control of self-directing their journey of physical activity management despite pain. There are three parallel journeys aimed at psychological, physical and self-management progress as shown in Figure 7-1. The journey is treated as a continuum where people's information and affective needs with

respect to pain management change gradually as they start gaining confidence and a sense of control in managing their activity using their own resources.

Three factors emerged as important for people with CP to be on the journey (as shown in Figure 7-1): (i) accepting that physical activity is important to maintain abilities and do valued activities, (ii) (re)adjusting expectations to reflect current ability levels, and (iii) taking responsibility for pain management. These are briefly described here:

(i) *Accepting that physical activity is important to maintain abilities and do valued activities:* Here, we refer to acceptance, not of the condition of CP, (even though that is considered important by the literature and in our studies) but of the fact that people need to manage their condition and their ability levels by doing physical activity rather than continuing the search for a cure as discussed in Chapter 2. Pain management physiotherapists reframe CP as a condition to be managed and direct patients towards more functional goals, away from finding pain relief (or mechanical models of pain). As POFB15 said, *“and I’m managing the pain rather than having an analgesic so a big motivation in doing the Alexander’s technique was to work very intensively [on improving physical capability].”*

(ii) *(Re)adjusting expectations to reflect current ability levels:* Expectations of what activity is sustainable despite pain and what people want to achieve need to be managed. Readjusting expectations to current capability when pain intensity is high or during setbacks is also important to staying physically active according to our findings and the literature in Chapter 2. Slow progress and small gains in capability to do activity discourage many people with CP and they may leave the journey. Aspects of this are discussed in the theme on “identifying affective barriers to physical activity” and “strategies for relocating locus of control to oneself.” PT3 explained, *“What do they expect to change and is that a realistic thing to expect and can we give them any knowledge or information about their body, or about fitness, or about pain that might help to adjust their beliefs or their expectations?”*

(iii) *Taking responsibility for self-managing activity:* People with CP needed to take responsibility for managing their physical activity as long-term healthcare support is not a viable option. PFG1 said, *“I think the biggest challenge is to understand that we have to manage it - with the support of other people - but we are the key rather than the external professionals”.*

From our studies, strategies emerged not only to address the physical barriers but also the psychological and the self-management barriers and to facilitate progress along each of the journeys. Physiotherapists used the metaphor of the *journey* in the way they shared knowledge and responsibility for pain management in the beginning of the process and gradually withdrew

support, transferring control and responsibility for the pain management process to people with CP as discussed in the theme. This progress from using the available support to developing skills for taking control of their own activity management is the motivation behind using the progression metaphor of a journey. The strategies that emerged (discussed in the next chapter) address and build upon the progress made along each of the three journeys rather than treating them as parallel independent ones. However, before progress is possible on the physical journey, some progress is needed on the psychological one. Similarly, self-management progress follows progress on physical and psychological journeys. Before discussing the strategies, we present the psychological barriers to self-management that have emerged from our data and how they interfere with adherence to physical activity in the following section.

7.2 Affective barriers that interfere with physical activity

As discussed in chapter 2, psychological barriers are critical in engaging with chronic pain self-management including physical activity. In our study as well, many affective barriers emerged that interfere with people's engagement with physical activity. However, what our results provide is an in-depth understanding of how these psychological barriers emerge from, are strengthened by and interfere with physical activity. Four subthemes were identified: (i) pessimism due to low worth of activity and high cost of pain, (ii) fear and anxiety can lead to avoiding physical activity, (iii) low mood interferes with ability to engage in physical activity, and (iv) feeling socially isolated restricts physical activity. Another affective aspect that emerged from our studies was loss of confidence in capability, but given its interaction with other sub-themes, it will be discussed within them.

The sub-themes that emerged are presented next. Within each sub-theme we present a table with the main codes related with the sub-theme.

7.2.1 Pessimism due to low worth of activity and high cost of pain

Pain was a recurrent subject in our data. It interfered with people's lives and activities and made them feel that the effort of engaging in physical activity was not worth it due to the high cost of pain.

P2 said, *"I tried doing them [exercises] and it made me [my pain] worse. It just wasn't worth it"*

P8: *'Oh what's the point in doing that, I did that before' I'd think it encouraged my pain so I won't bother doing it"*

Besides, the high cost of pain, restricted movements and slow increases in activity to avoid exacerbation of pain could make people lose confidence that they would be able to return to previous levels of activity. For example, some of the people we observed during group exercise sessions could stretch their trunk forward by only a few degrees during exercise, making it difficult to see the value in doing the movement. Physiotherapists also mentioned small gains could be demotivating for people with CP but felt that it was the only way to make progress without making their pain worse.

PTFG1: *“Most people struggle to see value in something that is very little if it's only very tiny amounts of exercise but in order to get the experience of doing something and not making yourself worse you need to experience trying it at a level that may feel quite low.”*

The rate of progress in increasing capability could be so slow that it was hard for the person to quantify or even perceive. Step counting was a typical measure that people used to quantify their progress using technology or measures such as distance walked.

P10 said, *“I mean sometimes even if I am indoors like I won't be going out today but I'll walk up and down the stairs, walking around; you know I don't have a big house but I'll do a couple of thousand (steps) a day just walking around the house, you know, making cups of tea and dinner and moving with that.”*

But increase in number of steps or distance covered could be very limited over short periods of time and rebuilding capability felt overwhelming resulting in further loss of confidence and reduced self-efficacy.

P1: *“ [...] 6 years ago I couldn't walk 25 m. I can now walk 5 miles, but if someone told me it would take me 6 years to rebuild that, I would never do it.”*

Decisions about activity were further influenced by pain intensity, often expressed in terms of ‘good’ or ‘bad’ days. Therefore, people with CP must cope with varying levels of capability for activity from day to day (or even at different times of the day) depending on pain levels. Some people with CP reported that they could not do any activity on bad pain days and emphasised the need to rest.

P6 said, *“On difficult days, I am paralysed with pain: I'm laid in bed. [...]”*.

For some people, when pain intensity was high (on a bad day), only activities that were very important to them could outweigh the high pain intensity and need to rest. While some others have preferred activities for bad pain days that make them feel better based on past experience even if they do not adhere to their normal routine due to pain.

P3: *“Walking is good for it, usually walking helps.”*

P5: *“I do try to do something because I've found that the more I do move about, it does help. It's terrible in the morning when I do wake up and my back is in spasm and I think, ‘oh how am I going to get out of bed?’ I hang on to the bedstead, and I pull myself up and I've found that a little bit of movement is better than none.”*

However, on good days of low pain intensity people could be prone to overdo activities.

P11 said, *“On a really good day, I feel like I can do it all, in fact I try to but I know I shouldn't”*.

While pain intensity fluctuations are not directly linked to the amount of physical activity and are inherent to the CP condition, overdoing activity can increase pain intensity and the need for rest, leading to a vicious circle. Overdoing activity during good days could be due to various factors such as the desire to regain lost capabilities or make up for the time lost in work or social life (e.g., catching up with work or spending time with children). These demands mean that people put their body under a sudden strong physical demand, which may result in over sensitization of pain pathways as discussed in Chapter 2.

P3 said, *“When I'm doing it (sewing), I want to finish or get to a point and I'll forget to stop or break or how long I've been going and by that time it's too late.”*

Sometimes pain may be due to re-engaging a part of the body that leads to underused muscles and joints becoming painful and increasing anxiety. Overdoing activities could also be a result of the activities being too immersive or enjoyable.

The fluctuation of pain intensity has further consequences on the perception of progress in gaining capabilities. Progress and gains in physical activity may dip further on bad days leading to further frustration and anger at the reduced capabilities. This is in clear contrast with the general definition of progress as steady-physical improvement that people have and expect when they talk about physical rehabilitation. In addition, the needs of having to constantly re-evaluate one's capabilities and the amount of physical activity engagement required each day further contributes to this frustration and to the loss of confidence in being able to manage function.

P12: *“I have to devote a fair chunk of my time and thought and energy and day to managing this damn condition I've got just to get through the day. If I don't I won't be able to. It would be very nice [...] to get out of bed and say I could do anything I like today and I don't have to stretch just to maintain my abilities. It would be nice to go to the kitchen and reach up to the highest shelf without pain or the feeling that I couldn't*

do it. So a great proportion of me is now devoted to this and that is a bit depressing. [...] it means less time to do things that are actually enjoyable or productive and that is part of the problem faced by people with my condition.”

Aside from bad pain days, prolonged setbacks due to the chronic pain condition, overactivity or other triggers, where pain levels flare up can also have a negative effect on people’s activity levels and undo physical activity progress. Setbacks take a psychological and physical toll on people with CP.

P1 explained, *“Setbacks are a complex issue, because if you have a setback for whatever reason, it’s easy to assume that you’re going to go all the way back to where you started and this can be very depressing”.*

Interviewed physiotherapists highlighted that repeated setbacks, limited progress, and diminished capability for functional tasks can be very disheartening in the long term for people with CP.

PT2 said, *“The corrosive effect of repeated flare-ups and of the fact that people feel that they’re not making progress. They don’t have someone to help reevaluate how much progress they’ve made. That often can mean that people start to slide down into depression, catastrophic thinking, and restrict their activities and interactions.”*

People with CP report frustration at having to rebuild their capability and the slow pace of progress, feelings of failure in self-management of pain, and hopelessness about their condition.

P2 said, *“and I guess to some degree the pain and the negative outlook in life take over where you just can’t be bothered and what’s the point.”*

The main codes identified for this theme are presented in Table 7-3.

Table 7-3. Main codes identified for present sub-theme

Sub-theme	Main codes
Pessimism due to low worth of activity and high cost of pain.	<p>Constant presence of pain interferes with activity</p> <p>Constrained movement and limited capability. Low perceived worth of doing activity. Cost-benefit analysis of doing activity</p> <p>Inconsistent progress: variability in pain levels (good days vs. bad days); setbacks and flare-ups reduce capability, reduced capability on bad pain days, overdoing on good days; being active vs. overactive. Disappointment due to lack of progress</p> <p>Feelings of frustration, hopelessness and low confidence in capability.</p> <p>Past experiences: Bad experiences with pain management, physical activity. Being very active before pain.</p>

7.2.2 Fear and anxiety can lead to avoiding physical activity

Pain-related fear and anxiety are experienced by people with CP when stimuli (wrongly) associated with pain are perceived as threatening (Gatchel et al. 2007). These states have a significant impact on the level of function and pain tolerance of individuals as they worry that if they increase their level of physical activity there would be a corresponding increase in pain (Turk 2002). In our studies, participants reported fear with respect to a variety of issues (what the fear is about) and terms to describe the experience were used interchangeably with others such as anxiety and worry. There are many reasons for developing fear or anxiety with respect to physical activity. Fear of pain exacerbation due to activity and of damage due to activity could be reinforced by sudden onset of pain during an activity.

P13: *“Often standing for a long period of time in public places is not good. I went to a standing Shakespeare performance the other week and that was horrific for my back.”*

P4: *“If I were to deliberately go for a walk and just did more everything I would say due to past experience, my mobility would be practically zero for at least 3 or 4 days afterwards so I get so much stiffness in my back and legs that I can't really walk.”*

Past experience of repeated pain onset when doing specific movements or activities could also reinforce the association between that movement and pain, with the consequence that people might avoid the now feared movement when possible. P12 reported anticipation of pain when doing certain activities that had caused pain in the past:

“Turning to look at things: the looking around part of the walking is a challenge and obviously the anticipation of the pain. I do get back pain if I go too far. I can walk now and I walk quite a lot but any thing too much and I will have pain.”

Fear of pain exacerbation or damage could also be as a result of overdoing activity in the past, especially on less difficult pain days as discussed in the previous theme. Overdoing activity could lead to increased pain or cause setbacks, need to recover, unreliable progress or anxiety and avoidance of activity as discussed in Chapter 2. Physiotherapists were mindful of how these emotional states affected the rehabilitation progress of a patient. They reported that fear of pain, and that pain meant damage were the most commonly reported deterrents to physical activity in patients.

PT2: *“when we see patients they've [...] tried exercise and often it has made their pain worse so therefore they are very apprehensive of trying exercises again”*

To function despite fear of performing certain movements people could consciously and often unconsciously start avoiding or restricting certain movements and lose confidence in doing them. These decisions (conscious or unconscious) of restricting/ modifying their movements were to protect themselves from pain (e.g., bracing, guarding). Unfortunately, although referred to as protective movements, such restriction of movement could instead exacerbate pain, worsen negative emotional states, and cause withdrawal from physical activity.

P8: *“I realise my posture has been affected by the deformity of my spine. But I also find I adapt my posture to counter any specific pains. This causes other problems in my body. I try to keep my sense of balance good.”*

This avoidance could be due to poor body proprioception or lack of coordination and muscle structure. The proprioceptive system in people with CP may be altered due to anxiety and increased focus on pain rather than on the movement. Bad proprioception and balance associated with CP is highlighted in the literature as well (Lee et al. 2010) which even suggests that proprioceptive senses in the body may have been switched to attend to pain rather than the body configuration. Our participants with CP also reported bad proprioception and balance, which made them feel vulnerable or cautious in doing certain activities that they enjoyed before.

P2: *“I used to love it but I'm so frightened because I've had a couple of bad falls - well several bad falls. And I'm frightened of falling over, so I don't do that any more, no.”*

All interviewed physiotherapists highlighted the connection between the emotional states and movement behaviour. For example, PT4 described an experience with a patient,

“a guy I had in clinic who came in absolutely literally scared stiff. This guy cannot move. He cannot forward flex. However, if you sit him down and you reduce levels of fear, he can actually reach down while sitting and touch his ankles. He wouldn't do it when standing because of fear”.

The above quote also shows the importance of context in the relation between fear/anxiety and movement. People can be afraid of doing certain movements in a particular context, where, for example, the context may be environmental (e.g., getting up from a new chair). It could also be associated when the movement is part of a more complex movement. For example, we observed that people could stretch their trunk forward while in a standing position, but may lack confidence when stretching forward was done as part of a more complex sit to stand movement. Physiotherapists reported that they often engaged with the person with CP to address fear of movement in anxiety-provoking contexts in CP to enable people to gain confidence in movement in those settings. Physiotherapists also tried to disentangle the relationship between

movements that a person felt confident in doing and the ones that were feared by increasing their awareness of their own movement capabilities and limits. PT3 said,

“Telling them the same things that I'm looking for and getting them to recognise it and to really analyse it themselves. People can become overactive and tense and can recognise that through relaxation techniques and stretches as well as cues of when they are getting overactive - guarding, tensing, holding their breath, that sort of thing”

The main codes identified for this theme are presented in Table 7-4.

Table 7-4. Main codes identified for present sub-theme

Sub-theme	Main codes
Fear and anxiety can lead to avoiding activity	<p>Past experience/ association of pain onset with movement</p> <p>Fear: of: (re)injury, damage, getting stranded, increased pain, further damage due to incorrect movements</p> <p>Lack of confidence in introducing variation to activity/ exercise routines.</p> <p>Altered proprioceptive feedback</p>

7.2.3 Low mood interferes with the ability to cope with pain and to engage in physical activity

CP interfered with people's enjoyment of activities. People reported that low activity days resulted from not just increased pain but also emotional distress and low mood as a result of not doing valued activities, and the cognitive and emotional load of dealing with their condition (Turk & Okifuji 2002). Participants reported how their activities and routine varied with their mood on particular days. While people were not always aware of how their mood affected their activity levels but on reflection most felt that they were more avoidant of activity when feeling low, irrespective of their level of pain. Some believed that when their mood was low they found excuses not to do chores. For example, P11 said,

P11: “Sometimes my mood is quite low and I find it quite difficult to motivate myself. When my mood is better I am able to do more, and I feel like doing more. Like loading the washing machine: I will convince myself that I don't need to do it today but on reflection, I know I am feeling low and a bit depressed and I don't want to deal with it.”

Others thought that it was their ability to cope with pain that was worsened by low or depressed moods. Expressing this, P9 said,

“I didn't realise how much my mood affected my pain - the pain is not worse or better but my tolerance is. If I'm sad or worried, my brain can't deal with pain. If I'm upset or in a low mood pain messages interrupt me rather than me dealing with them.”

Physiotherapists also reported that people's negative beliefs could influence their mood and stressed the importance of awareness of these links and of the unhelpful beliefs about the relationship between pain and physical activity. PT1 said,

“Teaching them to address their negative beliefs that are not a true reflection of what's actually going on or it's just a reflection of how they are feeling that day and then getting them to change their negative beliefs into positive and getting them to maybe stick it on their screen somewhere so that they are constantly reminded not to try and not go back into those negative thoughts that can affect their mood. “

Indeed, participants with CP felt that better awareness and understanding of their own psychological states and mood patterns could help them to identify potential triggers of emotional distress and enable them to reduce periods of low mood. Identifying triggers such as habits or routines contributing to low mood or distress could help the person make lifestyle changes—mental and/or physical. However, these triggers were not always obvious. For P9,

“Work was giving me stress, which was giving me pain and because of the pain I was getting more stressed so it was one big circle. So because there was something at work that I couldn't resolve I was frustrated [...], I couldn't deal with my pain so my pain levels got worse and I became a bit depressed because I couldn't break out of that cycle of frustration and you know all I could do was feel my pain rather than the frustration and it was really good to see that in a graph.”

Sometimes, people with CP reported that they did not even realise the extent to which they were affected by low mood. For instance, P8 said about being diagnosed with depression,

“A big part of having pain is having low mood or depression. Funnily I didn't realise until just a few years ago really that I was living with depression and I used to think, ‘ah I'm going to do my head in today’. [...]”

Some participants also highlighted feelings of hopelessness. Participants who had been previously diagnosed with depression and had lived with it for a while reported that they were more sensitive to their mood. For example, P2 who had been previously diagnosed with depression said,

“If I'm on a downer - one of the traits of depression - you just don't feel like doing anything and I keep my mouth shut. And then when the mood is lifted, you can do things

you find enjoyable. I suffered for many years [with depression] and I've learnt to recognise when you're on the slippery slope downwards and I've learnt to recognise when you're crawling back out of it"

For this participant, when he experienced low mood, he would get quieter with his wife as he found that he got more easily annoyed which was difficult for his wife; this in turn worsened his own mood leading to a vicious cycle. Some participants felt that logging mood states would be helpful to them and help loved ones to understand what was going on with them.

P2: *"the depression: you're up one minute down the next and there seems to be a cycle and, well I don't log it but it's a good idea, why don't I (laughs) ..."*

Logging their mood and related pain/ activity levels could help people to recognise when the depression was getting worse and keep track of bad days, good days and progress. Further, it could provide insight into the connection between activity levels and mood states. However, the problem with detailed logs of pain, mood, and stressors is that the healthcare provider may not always be available to analyse it for the patient. Besides, continuous self-logging of pain and stress over long periods could result in staying focused on the pain, which could have a negative impact. However, participants suggested that such technology could be a tool to allow them to reflect on their wellbeing. On this subject, P1 said,

"An individual knows best how they're feeling but you can get all that babble in your head that can easily confuse the messages. If technology enables you to clearly see or think about and reflect on how you are feeling or to self-assess, that would be helpful!"

The main codes identified for this theme are in Table 7-5

Table 7-5. Main codes identified for present sub-theme

Sub-theme	Main codes
Low mood interferes with the ability to engage in activity	<p>Low mood due to pain/ focus on pain, tiredness</p> <p>Emotional barriers: Low mood, depression, hopelessness, anticipation of pain, loneliness, stress, boredom, guilt.</p> <p>Low mood due to bad weather</p> <p><i>People report technology use for logging, tracking mood/ pain.</i></p>

7.2.4 Feeling socially isolated can restrict physical activity

The social world also presents many barriers for people with CP (Benjamin et al. 2012; Felipe et al. 2015). Having CP is socially isolating and people reported feelings of loneliness, losing

friends because they could not keep up with social activities, and feeling misunderstood and judged by others because of the ‘invisible’ nature of CP.

P14 explained, *"People will comment, 'but you look so good!' They're like 'You aren't disabled, why do you have a disabled badge?' Almost like they think it's illegal. It's not obvious you see but that little walk in the parking feels to me like running a marathon, or the olympics - every joint hurts."*

Many participants reported that they avoided going out for fear of unanticipated physical demands or mishaps that are beyond their physical capability to manage (e.g., crowded trains where they might not find a place to sit, long queues). They expressed a fear of social disapproval in public places because having to manage their pain may mean behaving differently from others (e.g., having to sit down at any opportunity in public). Embarrassment was also reported in situations where they may need to ask for help or may not be in a position to offer help when it would be usual to do so (e.g., giving up a seat to a pregnant woman). People fear that they will be shouted at or glared at or abused if they ask someone for a seat on public transport or not get help if they fall in a public place or if they get stranded somewhere because of an onset of pain. For example, P3 spoke of not feeling safe if she left the home on her own, *"Well, its just that I worry that I may get stuck in the middle of somewhere, because my pain can come on quite quickly. So I don't do it [go out alone] or only feel secure when I am with someone. If I get stuck it doesn't matter and it's quite safe as well."*

Barriers also extend to the physical environments that people with CP use for doing more physical activity such as the lack of local pain management groups, lack of gyms or other physical activity areas in their vicinity or even fear of injuring themselves or finding obstacles to activity in places like gyms and swimming pools or other life concerns.

P2: *"I love going swimming, I adore being in water but again the thing that puts me off is having to get changed. It's just a nightmare."*

P4: *"There was no group local to me, not at the moment."*

Some participants reported that they were tired before they actually started doing an activity just because of the process of getting there (and possibly the anxiety of getting there as discussed earlier). Given the accumulated fatigue or muscle tension due to anxiety and then doing the activity itself could result in increased pain. P16 said,

"Even going to the pool, which I loved to do, even walking in the water – it gives me such a huge flare-up afterwards and it's quite a long way from my house. So with the travelling and the getting changed and everything, I do find that too much these days."

The four subthemes discussed above highlight the complexity of the psychological barriers and how they interact with each other as well as pain and how they interfere with physical activity. There are other barriers such as financial and practical barriers that came up in our studies, but these were not the focus of our studies and are not addressed by this thesis.

The main codes identified for this theme are in Table 7-6.

Table 7-6. Main codes identified for present sub-theme

Sub-theme	Main codes
Feeling socially isolated restricts physical activity	Loneliness, loss of friends, being misunderstood by friends/ family/ others. Fear of being left, stranded, or stuck because of sudden onset of pain, or falling Anxiety of pain onset in public places due to lack of facilities/ crowds/ social norms, feeling vulnerable because of inaccessible facilities Social disapproval, embarrassment <i>Use of technology to be in touch with others</i>

7.3 Chapter Summary and Discussion

The findings reported in this chapter reinforce the importance of psychological barriers in CP self-management in general and in the engagement with physical activity in particular. It is only recently that CP has been proposed as a disease (Tracey & Bushnell 2009) and integrated biopsychosocial frameworks (Gatchel et al. 2007) have been used to describe the interaction of physical, psychological and social factors in the propagation of pain, and in the impact of pain on quality of life.

Our results highlight how learning to engage with physical activity requires not just physical progress but also psychological progress. Psychological progress is not only about overcoming fear and anxiety and gaining confidence in doing movement or activity, but it is also about gaining the confidence and capability to self-direct and self-manage physical activity (e.g., confidence in increasing demand or progressing to a new challenge). These findings indicate the presence of three parallel journeys for overcoming self-managing physical activity despite barriers in CP. Further, these three journeys interact with each other and progress within them is interconnected.

In addition, and differently from other conditions, this *journey* is not a linear one. Unanticipated increases in pain generate anxiety about harm and lead to avoidance. Bad days and pain-related

setbacks may require a re-assessment of physical and psychological capabilities and a re-assessment of pain management guidelines for re-engaging with activity (e.g., reducing targets until recovery). This means that people need to be able to accept the setback and recognise the need for taking a step back in the progress they may have achieved.

If we look back at the technology discussed in chapter 4 and the theories they build upon presented in chapter 3, we can now better understand limited use of such technology in self-directed CP physical rehabilitation. Also, simply reusing technology designed to motivate physical activity for other conditions such as stroke (e.g., Rosati et al. 2013) may be misguided. Rehabilitation technologies (e.g., Schönauer et al. 2011) mainly use traditional clinical models for physical activity, where psychological factors are addressed by the presence of clinicians or physiotherapists. Even recent technology developed by the SMART2 project (Duggan et al. 2015) to motivate people in doing more physical activity in the home by tracking and giving feedback on the number of steps they take, falls short in addressing these identified barriers. While technologies such as SMART2 are beneficial, they depend on clinicians or researchers to set goals and pain management targets on the system. Our findings demonstrate that setting targets and goals in the presence of pain is psychologically challenging for people with CP.

Simply designing technology that promotes physical activity with no regard to emotional factors may further expose people to a negative experience of movement or to feeling isolated with their difficulties as reported in CP blogs. It is hence important that these mechanisms are addressed and incorporated into design of technology for physical activity in people with CP. In the next chapter, we report the findings on the strategies that emerged from our studies to address the psychological barriers identified and to learn skills for self-directing activity in CP.

Chapter 8 User study findings: strategies for physical activity support in people with CP

In the previous chapter, we listed the five themes that emerged from our studies and presented the first two of those themes, i.e., the concept of the journey and the affective barriers that interfere with physical activity in people with CP.

In this chapter, we focus on presenting the remaining three themes that focus on strategies for self-management of physical activity. The three themes that will be presented in this chapter are: (iii) strategies for relocating control for physical activity in oneself, (iv) strategies to explore, build and maintain activity for everyday functioning, and (v) (re)building social alliances. The themes and their descriptions are listed in Table 7-1 in the previous chapter.

Next, we discuss each theme for informing the design of technology for physical rehabilitation in CP.

8.1 Strategies for relocating control for physical activity in oneself

Beyond needs and barriers to physical activity, a rich picture of strategies used by physiotherapists and people with CP also emerged from our studies. These strategies were used to overcome affective barriers to physical activity, discussed in the previous chapter and are based on all three parts of the journey: physical, psychological and taking control through developing self-management skills.

These strategies could be divided into three recurring phases of the pain management journey that we identified. While the pain management journey was presented in the previous chapter, we present the phases here because they enrich the understanding of strategies. The three phases are: (i) explore physical capability and psychological capability (set baselines), beliefs and expectations from activity (ii) build on current physical and psychological capability, and (iii) maintain gains. The phases overlap, so it is not a case of exploring, building and maintaining as independent constructs but they influence and interact with each other. In case of setbacks, adjustment may mean that capability is reduced in the short term and people may need to go back to exploring and rebuilding their capability.

Exploratory phase

Exploration of capability for physical activity despite pain was described by physiotherapists as setting initial baselines for different activities, not by requiring physical performance but by “*what they feel that they can do.*” (PT2). This may be supplemented by functional tests or observation to assess challenges to physical activity, such as muscle stiffness or tension.

PT3: “*because for lots of people maintaining and building up physical fitness seems to be challenged very much by their periods of very low activity in a flare up.*”

At the beginning of starting any programme of activity, these activity levels need to be set at a level that is comfortable for the person to achieve without anxiety and without triggering pain. In case of setbacks the exploratory phase may need to be revisited.

Gradual building phase

This builds on the baselines by steady increments: both people with CP and physiotherapists stressed the importance of building slowly otherwise they risk having setbacks and flare-ups in pain.

PFG2: “*It is quite interesting initially how little you can do but that if you just do that very, very little, how quickly it builds, but if you think, well, I did one today I'll do six tomorrow, you're going to go backwards.*”

The building phase is not just about building physical capability but also psychological capability, such as self-awareness and self-efficacy and strengthening pain management principles such as pacing, taking breaks, stretching through practice.

Maintenance phase

Building activity leads into a phase of maintaining gains.

P1: “*I walk every day ... on an ordinary day, I do something like half an hour, or 40 min where I do it in small chunks: roughly 10, and 10, and 10 minutes*”

This phase is important as most pain management programmes and exercise programmes report a reduction in exercise adherence following completion (Lewthwaite 1990; Prochaska & Velicer 1997). Physiotherapists felt that maintenance of physical activity was more likely if individuals found it interesting and rewarding and use pain management principles (Wigers et al. 1996).

To do self-directed physical activity and movements that people with CP tend to avoid, it is important that they feel in control of these movements, feel that they are able to judge their movements and build a sense of control in individual movements and activity in general. Four

sub-themes emerged: (i) enhancing self-awareness improves confidence in activity, (ii) strategy to move “*with the flow*” rather than “*correctly*”, (iii) associating positive feelings with activity boost self-esteem, (iv) taking control of activity improves ability to self-manage.

The sub-themes that emerged are presented next. At the end of each sub-theme we present a table listing the main codes related with the sub-theme.

8.1.1 Enhancing self-awareness improves confidence in activity

Increasing people’s awareness of their body, body position and body movement emerged as important factors in addressing a variety of psychological barriers as well as providing the information and skills for facilitating activity self-management. Physiotherapists focused on supporting people with CP to increase their awareness of their movement capability (and limits), breathing, and body sensations while doing movement (e.g. muscle and facial tension). Many people with CP who had been on pain management programmes reported that they were more aware of the way they used their body for activity.

P16: *“I used to stand and sit without thinking how I stood or sat, but now I’m very aware of my body. When I stand, I stand with my legs shoulder-width apart for balance and stability. I’m doing it now while talking to you.”*

Physiotherapists encouraged people with CP to be aware of their physical and psychological limits in performing a movement or an activity (e.g., how long they could stand/ sit, how far they could stretch before tensing up). They encouraged people to move to a point that they felt confident to move to, rather than setting targets beyond it. The rationale was to avoid increasing pain due to overdoing movement that could lead to more anxiety and strengthen associations between movement and pain. Instead physiotherapists focused on building confidence in movement before suggesting gradual increases, which could enable people to build ability.

People with CP reported that awareness of limits in addition to ability was indeed important when planning activity and made them feel more in control of their activity despite pain.

P4: *“before I couldn’t carry even 400 grams and, after [...] like in two years, I am able to carry like half kilo, one kilo. But I cannot carry weight for a long time...”*

In the above example, P4 knew her ability had increased. However, she was also aware that she would be in pain if she carried that weight over a long period. Keeping such limits in mind can help people to be more active and to improve their abilities through graded increases.

Physiotherapists also called attention to unhelpful behaviours and provided cues and helpful hints about tension and painful movement throughout their sessions that people could use when

self-managing activity. Real-time cues while doing an exercise, such as reminders to “*breathe, relax your face, and drop shoulders*” (in observed group sessions) helped to improve people’s awareness while they were performing a movement and at the same time facilitating relaxation and reducing the chance of increased pain. For example, OPT2 said, “*If you are grimacing or your face is getting tense, you may be pushing too far.*”

Many people with CP also felt that they were more aware of other body sensations, such as breathing and body tension, that could lead to pain and they try to address these.

P9: “*one thing I realised I was quite bad at was breathing. When I am in pain I tense up and hold my breath a lot and that stops me well it just bungs everything up and means that I actually feel in pain more*”

Beyond awareness of breathing, physiotherapists encouraged people to focus on counting breaths, rather than on the duration of the exercise or maintained pose. This could be especially useful for a demanding exercise, and was associated with controlling breathing to relax, while modelling how the patient could do the exercise when alone. As OPT1, “*We want to encourage people to hold the stretch for at least 10 to 15 seconds, up to 30 seconds, but trying to tie together working out ‘how many breaths do I take during that time’ and using that to count can work for making sure they are breathing through the exercise, but also putting a bit more of the responsibility on them to choose: ‘OK I’ve done enough of this now. I’ve done my ten seconds.’ Then that habit might be a bit easier when they’re on their own.*”

Awareness enhancement was also used in relation to strengthening knowledge of pain mechanisms and pain models. For example, OPT2 said, “[...] *(we try) to reinforce that kind of (biopsychosocial) model, so if ‘my pain is sensitivity in my nerves’ that hopefully links them a bit more to the pain mechanisms model rather than to their pain being caused by a structure or change.*” They also reinforced the relation between muscle activity and function.

The main codes associated with this sub-theme are in Table 8-1.

Table 8-1. Main codes for enhancing self-awareness sub-theme

Sub-themes	Main codes
Enhancing self-awareness improves confidence in activity	<p>Promote mindfulness and awareness of movement: awareness of body while moving, awareness of overdoing, tension, guiding attention, reflect on activity, thoughts, find own rhythm of movement, comfortable pace</p> <p>Build self knowledge: awareness of limits, self monitoring, doing what you can</p> <p>Attention to positives: Focus on breathing, visualise calm situations, focus on pleasurable sounds (e.g. music), focus on feeling in control</p>

8.1.2 Moving “with the flow” rather than “correctly”

While physiotherapists addressed pain-related behaviour patterns by bringing them to the attention of patients, they never suggested that a movement was “wrong” or “not safe”. They emphasised that people must stay active and keep moving. However, most people with CP were concerned about maintaining correct postures and moving “correctly” to avoid injury and reap the benefits of exercise.

FG1P1: *“I know which of my muscles is not likely to respond in a traditional way and so it's actually almost thinking through movements like, I'm going to stand on the ground and I'm going to put my left leg on a step and I'm going to push through my heel and I'm going to bring my right knee up [...]”*

Physiotherapists stressed that it was erroneous to suggest that there was a “correct” way to move as this implied that there was an “incorrect” way of moving that can cause damage. They emphasised that continuous corrective feedback could reinforce wrong beliefs people have about the relation between pain signals and injury in CP.

PT2: *“In that example of bending your knees or you will hurt your back, it's all very relative isn't it. I mean, if you're picking up a pencil who is to say that you will hurt your back or not. It's more if you're used to doing that movement or not. [...] so we try not to perpetuate any kind of belief that certain movements are bad or wrong”*

Rather than correcting movement, physiotherapists focused on tackling the underlying pain belief, which could make people more confident in doing the activity.

PT4: *“So for example explaining why they might be getting clicking [in joints] can help them and they say, ‘Well, great! Now that I don't have that to worry about I seem to be much more confident.’”*

Physiotherapists felt that more than moving correctly, people would be more confident in doing a movement if they had a sense of control over it. In that sense wanting to know precisely how to move and what to avoid could be associated with achieving that sense of control rather than necessarily about doing things “correctly”.

FG1PT1: *“there is not a lot of evidence to support any sort of core stability that most people know about. [...]. We all have experiences of things that we think help [...], it's because you've tried things and found what works best for you and that's up to us when we do something, I wonder if it is more about the sense of control we get from doing something that we think helps us”*

Instead of focusing on correction, physiotherapists suggested that staying mobile and using pain management principles could help people to manage activity more successfully rather than focusing on doing activity in a particular way.

PT3: *“our focus is more on dynamic posture: keeping moving or moving when required so you're not stuck static in any position for long enough so you're making your pain worse. So that is more of our focus than keeping your back straight or knees bent...”*

While physiotherapists never suggest alternate movements as a safe or “correct” way of moving, they could provide advice to make a movement *easier* for people to manage when on their own.

PT2: *“we might say in our group, for example, if you're lifting a very heavy weight, it may be easier to lift by bending your knees because your leg muscles are powerful”*

To make movements easier for people with CP, physiotherapists also give movement cues, alternatives to stretches, correct pain related beliefs and break down movements. For example, to practise a sit-to-stand movement which people with CP find difficult, physiotherapists may ask them to practise just the reach forward aspect of the movement and gain confidence in that.

Besides corrective feedback, people with CP felt that reassurance of the safety of exercises could help them be more confident in movement. Physiotherapists felt that since the movements were not damaging, corrections could be minimised in favour of reassurance until the person was more confident in doing them. Such reassurance could also be delivered in the form of addressing beliefs that people with CP held and strengthening pain management principles.

PT3: *“In terms of the pain in the back sitting with your legs crossed is no worse than sitting with your legs uncrossed, in fact some people find it easier. But if we overdo it, then it could be a problem so it's about remembering to change position regularly.”*

People were asked to leave out movements that caused them pain or anxiety. Physiotherapists provided the option for people to tailor the exercise protocol so that they could succeed in doing movements that they found challenging. OPT2 explained, *“The ultimate aim is for patients to move with confidence, rather than moving in a way that we want them to move, where they might not feel confident at all, so that's why we are very careful not to install any fear in patients about how they should be doing the movement”*.

The main codes associated with this sub-theme are in Table 8-2.

Table 8-2. Main codes for current sub-theme

Sub-themes	Main codes
Strategy for moving “with the flow” rather than “correctly”	Barriers: fear of pain, damage, injury. Past experience Address pain beliefs: describe behaviour, consequences, beliefs; behavioural experiments; providing non-pain related examples reflecting on past experience. Correct movement vs. make it easier, address beliefs, reassure. Continuous correction reinforces pain beliefs, undermines confidence.

8.1.3 Positive feelings associated with activity boost self-esteem

Almost all participants agreed that encouragement and positive reinforcement were key factors in motivating them to maintain a programme of physical activity, particularly when they had more pain. There was consistent attention from physiotherapists to increasing positive affect associated with exercise and movement, explicitly to increase motivation. During one of the pain management education sessions, a physiotherapist emphasised that reminding people of their progress could motivate people who were struggling with activity.

PT1: *“Lots of positives, reinforcement [...] lots of positives, lots of encouragement, lots of reinforcement really about why they need to do it, keep on explaining the benefits of it, just lots of fine tuning, lots of guidance, and lots of positive support”*

The interviewed physiotherapists also highlighted how technology could help by giving “positive feedback” (PT1, PT2) and “reinforcing positive emotional behaviour” (PT3).

P6: *“It might help if it (technology) could remind me how I felt after exercise and adapt to my pain”.*

Physiotherapists used open and loose descriptions of exercises rather than providing specific goals to be achieved or anatomical descriptions of performing a movement. They preferred people to use their own bodies as a guide to movement. Thus, people with CP were encouraged to move in ways that they found practical rather than focusing on “correct” movement as discussed in the previous sub-theme. Physiotherapists always ensured there was always an achievable target and therefore the basis for positive feedback.

Physiotherapists also used carefully phrased verbal expressions to engage people in feared activity and facilitate self-esteem. For example, physiotherapists selected inclusive words and present participles to give instructions so that people were already engaged in a movement before they had appraised it.

OPT3 said, *“If we tell the patient 'Next stretch you're gonna have to bend forward', for example, you might already trigger some areas in their brains that go, 'Ooooh, bending forwards is really bad', but if you just start doing it and then talk through it as you're doing it, there's something that says to them, 'Oh, actually I am bending!' .*

This helped people to stay focused on the movement and the feeling of moving rather than focusing on reaching a specific goal. This strategy also focused their attention on the movement so they could enjoy the movement as they realise that they are performing it. Physiotherapists also focused attention on breathing during movements so that people could do the movement longer with more control and derive more pleasure from it.

Doing movements with more control also gave a sense of satisfaction in doing movements because some people with CP rush through movements to finish them quickly and *“get it (exercise movement) over with”* (P6), rather than do it slowly and focus on the movement

P12: *“you're supposed to do it slowly and we are inclined to do it very quickly but the benefit is in doing it really slowly and learning to enjoy it.”*

While people with CP acknowledged that real-time positive reinforcement provided by physiotherapists was motivating, this support was not available when people were doing physical activity on their own. People with CP felt that if some of the emotional support provided by physiotherapists could be provided by technology, it would help them to self-manage their physical activity. This support could include reminding people with CP of positive feelings and making suggestions about activities that people had enjoyed in the past even when they were feeling low or avoidant. Technology could also recommend activity based on people's ability, level of activity, pain and mood and guide them through doing the exercise.

P12: *“something [...] which suggested what exercise needs to be done [...] an app with different exercises that could analyse or construct the program for you and instead of doing the same thing you do everyday, it be quite active in suggesting exercises. When physios talk you through it: timing is very important; breathing is very important and relaxing. Like when you're doing Tai Chi, and [...] having that third party reminding you, I think I would find that really useful.”*

Logging mood levels before and after doing activities could also help with remembering and tracking positive feelings associated with activity.

The main codes associated with this sub-theme are in Table 8-4.

Table 8-3. Main codes for current sub-theme

Sub-themes	Main codes
Associating positive feelings with activity boost self-esteem	Positive reinforcement: encouragement, reiterating benefits, providing support Reminders of positive feelings/ sensations after exercise. Exercise suggestions based on mood.

8.1.4 Taking control of activity improves ability to self-manage

A few people felt that they could not make gains on pain management programmes that they attended because they needed more support from physiotherapists to manage their activity.

P2: "They didn't impress upon us that if you're having a bad day come and see us. The impression I got was that you've been on it, here's what you've got to do, if you don't do it, well, 'Cheerio! You are now what you're going to be.' So I've never felt able to go back, both times."

However, due to limited clinical resources, such ongoing support is not possible from physiotherapists or pain management programmes. People with CP had to learn to self manage their activity in everyday life based on what they learnt in pain management programmes. This involved instilling a sense of control into those who lacked it or transferring a sense of control to those who located it in the physiotherapist or medical institution.

PT2 said, "Our job is to give them some kit and then they try to put that together to work out, to problem solve how they're going to approach a given task."

Physiotherapists generally gave support in the form of skill transfer and problem solving rather than solutions.

PT2: "the focus is very much on getting them to problem solve because in the long run to sort of help with self-management, that's what they need to be able to do."

Problem solving could help people feel that they could bring a situation under control even if it appeared overwhelming at first and was a focus in the pain management introduction session. During the session (described in Chapter 6), when participants were taken on an outing with a pain management physiotherapist and/ or psychologist and were queuing for tea, they were encouraged to find ways to pace themselves and take breaks. They were asked to think about cues related to when they would look for a place to rest. For example, based on their pain level or time elapsed since last break and they were encouraged to make the choice and later reflect on it with the group. If people felt that they were having trouble with any activity, rather than

demonstrating the activity and prescribing solutions, physiotherapists did the activity with the participants and reflected on the problem with them to solve it collaboratively. PT3 explained,

“we tend to do something more on the lines of a behavioural experiment than demonstrating the right way so we tend to maybe do more of let’s go and do this thing together and then talk about their experience and talk about ‘well what was difficult about that, what might be helpful to do differently?’ so the onus would be on them”

Initially, when setting baselines and initial levels of activity, physiotherapists left the decision with people with CP and worked with them to set baselines based on their recall and experience of their own activity.

PT3: *“initially we’d encourage them to find a baseline, and we describe that to them as an amount of activity that doesn’t cause an increase in pain at the time or later”*

The strategies to enhance awareness of movement and associated body sensations discussed earlier were important here for deciding about body capabilities and being confident in them. Physiotherapists also provided people with a sense of control through giving them options for exercises/ movements so that people could use what best suited them. By initially simplifying the exercises the patients had to carry out, physiotherapists attempted to reduce the occurrence of flare-ups, and to build confidence in the patients that they could safely and effectively do the exercises on their own.

PT2: *“focus on principles of taking it slowly, stop at the right point, continue to focus on their breathing. We give them examples of they can do it sitting or standing.”*

However, people also needed to progress. So, physiotherapists then worked on progression of the exercises that consisted of variation as well as increases in range or number or duration, using techniques of graded exposure, which add demand only when anxiety has sufficiently reduced. PT4 said, when inviting us to observe a mixed ability session:

“They need to understand that it does not matter how much they do and you can see in the session that they are at all different levels – so we don’t do a target movement or set a target movement that we think they might feel is the ‘perfect’ movement or feel they haven’t done it right. It’s about trying and moving and doing it often”

Discussing how to build up activity was another way of building control. Physiotherapists worked towards making people with CP feel in control of their movements so that they engaged more with movements that they tend to avoid. P3 explained,

‘When you have pain in a part of the body, your brain sometimes loses the ability to control certain segments of muscles, so it gets harder for people to do very local specific movements of painful parts of the body. That’s one of the reasons why we break down movements, to move specific parts of your body without anything else.’

For this, feedback was used carefully to imply that the control was in the person with CP. Negative feedback was used with care since it risked making the patient feel stuck in relation to that movement or activity. If negative feedback was given, it was usually accompanied by positive feedback, which, by contrast, reassures and encourages by identifying what patients can do despite pain and within their current limits. Positive feedback also undermined judgements about right and wrong ways of doing every movement, which can be associated with safety or threat, and sustained motivation. The amount of positive feedback provided was, however, gradually reduced to facilitate independence and to avoid patronising the patient as they achieved more control and confidence in their movements. PT3 reflected,

“The first time they do a movement, they bend, they stretch, you want to acknowledge that and ask them about it but you have to reduce that gradually – otherwise it is not motivating”

Another technique that physiotherapists used was generalising movements. This involved making people aware of movements that they were confident in doing and highlighting related movements in which they lacked confidence. For example, if a patient avoided bending to stand from a chair, physiotherapists might highlight when they were bending for other activities that used similar movements or talk about other activities that use the movement. For example, a bending exercise could help people to tie their shoelaces or pick things from the floor.

The main codes associated with this sub-theme are in Table 8-4.

Table 8-4. Main codes for current sub-theme

Sub-themes	Main codes
Taking control of activity improves ability to self-manage	<p>Simplify movement: Break it down into simpler parts, focus on breathing, mindfulness techniques, providing options, suggestions to make exercise easier</p> <p>Feedback: Maximise positive feedback, Reassurance, Minimise negative feedback</p> <p>Problem solving: behavioural experiments, reflecting on activity, reflecting on challenges; introducing variation, open ended instructions, assist in modifying plans of activity</p> <p>Shared decision making: Deciding baselines, deciding goals, support choices</p> <p>Skills: Generalising movement; Minimising physical help; Decreasing amount of feedback/ support; withdrawing support</p>

The themes discussed above focused on the development of strategies for people with CP to take control of their physical condition, supported by physiotherapists. We also discussed how each strategy addresses psychological barriers. However, it also emerged from our studies that people adapted these strategies and used them in different ways for everyday functional activity. The next theme discusses how people apply strategies for exploring, building and maintaining capabilities in everyday life.

8.2 Strategies for everyday functioning

As discussed in the first theme, people explore their capability and limits for activity, build incrementally and work on maintaining their activity goals. The strategies identified in this section are adapted and applied by people with CP or recommended by physiotherapists to improve everyday functioning in these phases. From our studies, an important set of strategies emerged to address the barriers in the previous theme and in particular the pessimism due to low worth of activity and high cost of pain, loss of confidence when engaging with activity, fear and anxiety associated with movement, low mood and feeling socially isolated. Four sub-themes that emerged are: (i) embracing pain management strategies can reduce barriers to activity, (ii) everyday function is rehabilitative exercise, (iii) developing routines and habits can help to maintain activity, and (iv) rewards and seeing progress are motivating. The sub-themes that emerged are presented next. At the end of each sub-theme we present a table listing the main codes related with the sub-theme.

8.2.1 Embracing pain management strategies in everyday life

In this sub-theme, we discuss the strategies and cues that the physiotherapists demonstrated and transferred to people with CP for their use, not just in functional everyday activity, but also exercise in the absence of the physiotherapist. These strategies include breaking down movements, going through the steps of doing a complex movement, being more aware of body sensations (e.g., tension), being mindful of physiological cues (e.g. breathing) and stretching before and after a movement. Also physiotherapists suggested starting small and building capability gradually: for example, if people found it difficult to lift weights, they were encouraged to start by lifting the smallest weight that they could without causing an increase in pain and then slowly build this up.

People with CP had strategies for executing activities despite pain. One of the most commonly used strategies was activity pacing, also discussed in Chapter 2. A way of pacing activities, used

by most people with CP in our studies, was taking regular breaks while doing household activities (e.g., *washing dishes* (P3) or *working on the computer* (P2)).

P4: *“I do something like 30-40 minutes in small chunks: roughly 10, 10 and 10 minutes. I’m okay as long as I do a 20 minute or half an hour walk at a time, I really think about that and track it but that’s roughly what I say.”*

P3: *“Like I stop: whenever I’m washing the dishes or something I will ensure that I go and lie down. Not necessarily on the bed or something but I’ll lie down on the floor or I’ll take a little break for 5 minutes and come back to it. So I pace myself in that way.”*

Taking breaks could be done by timing activity (e.g., take a break after every 10 minutes of doing dishes) or by quota achieved (for example number of steps climbed). A few people reported breaking up activities into manageable chunks (activity chunking) and tackling a chunk at a time as a way of pacing. Others found that instead of taking a rest break, they found it helpful to alternate activities so they were not doing any one type of activity for too long. Others ensured that they frequently changed positions, performed stretches, or rested.

P12: *“I don’t do things long enough. I alternate them. I might be painting for a bit and then I go out in the garden and then I do something else or take myself off to the shops, not particularly to buy, but the walk. Something different.”*

Others used pain as a measure of when to stop doing activity or take a break.

P3: *“Just to, to do a little bit, to notice how it affects your pain, take a break and then come back to it: you know, not to push beyond limits”.*

Some had tried basic CP apps with timers or kitchen timers that indicate through an alarm a reminder to pace or change activities. However, they found these reminders insufficient and felt that they needed more information to pace and vary their exercise routine.

Planning activities in advance was another way suggested for pacing activities so that people did not have to rush or cause a pain flare up because they do not have the time to take a break. Giving themselves time and planning activities in advance could also help to facilitate a sense of being in control of their activities and their day. External cues such as the music that people listened to could also enhance control over and pacing of certain activities. For example, physiotherapists recommended that people should listen to slower paced music to control the pace of doing an activity where they felt they could cause a flare up by going too fast.

Another strategy is for people to find activities that they enjoy doing and work towards valued goals. Physiotherapists ask about activity history, current activity patterns and what people’s

values and goals are in terms of activity before suggesting an activity plan. In some cases, the activity itself is the aim, what they want to do, and they just need to build their capability (e.g., walking); in some other cases it is more about using the activity or exercise to build up to a goal (e.g. stretches).

PT2: *“we identify goals and values for them and then working out what activity that might involve and then working out what they should do at the moment”*

Many people reflected on past experiences of activity where doing certain activities had triggered a flare up and how they avoided those activities. Pain management physiotherapists encouraged doing avoided activities but by allowing people to focus on activities and movements that they wanted to do to and to tailor their activity programmes in this way. The main codes associated with this sub-theme are in Table 8-5.

Table 8-5. Main codes for current sub-theme

Sub-themes	Main codes
Embracing pain management strategies can reduce barriers to activity	<p>Reiterate pain management principles: pain related information; address pain beliefs; manage expectations.</p> <p>Finding the right activity: meaningful, enjoyable</p> <p>Pacing: regular breaks, change position, activity chunking, pain awareness, alternating activities.</p> <p>Listening to the body: learn to stop vs. warnings.</p> <p>Physiotherapist aims: set baselines, explore capability, address beliefs and barriers, address past experiences, set goals, manage expectations</p>

8.2.2 Everyday function is rehabilitative exercise

Our studies indicate that functional activities are the primary form of physical activity in the homes of people with CP rather than exercise. Interviewed physiotherapists reported that they commonly divide activities into domains: the physical (e.g., exercises), functional (e.g., housework, everyday activities), and social (e.g., being with friends and family). They recommend doing functional activity rather than routine exercises and often suggest ways of incorporating exercise into everyday routines as doing so can help people to achieve valued goals. This is not just inherently rewarding and motivating for people, but also obviously demonstrates improvement in capabilities.

PT3 *“Just building up the muscles to do an activity does not translate into confidence in doing the actual tasks that people want to do.”*

PT2: *“People do get very bored by a list of exercises and [...] they've got reams and reams of exercises but they're not adding up to the functional change that they want.”*

Most participants in all studies treated household responsibilities as necessary functional activities that need to be done in the home. However, in other cases, participants actively did housework as a form of exercise, and treated it as an opportunity to strengthen physical capabilities.

P8: *“I will in the kitchen put things a bit higher that I find hard to reach. So I have to ... you know it makes you. It's frustrating but it makes you stretch a bit far and I use little things like that.”*

Household responsibilities were treated as necessary functional activities that need to be done in the home. Participants were motivated to do functional activities or integrate stretches and exercise into existing routines with an inherent purpose as they have explicit value in daily life and are the end goal of rehabilitation. Only half of the participants regularly performed exercise/stretches. Some of them reported that exercise was not a high priority as functional tasks took up much of their time and energy. This contrasted with others who were motivated to do functional activities or integrate stretches and exercise into existing routines. Functional activities also helped people to move the focus away from pain to the task or goal at hand.

Physiotherapists recommend that even within functional activity, people need to start at an achievable level and gradually build up their capability. Both being able to do a task repeatedly and then being able to build it gradually can add to feelings of self-efficacy.

PT3: *“They might need to start off doing three steps carrying a newspaper. And then gradually build it up and build it up. So we use the actual activity as the exercise rather than prescribing more static kind of anatomically based exercises.”*

Participants often adjusted their activities to cope with the pain, pacing according to physical capability or temporal patterns of pain and energy.

P4: *“I find things easier to do during the day. By evening I start to get tired and achy so I don't go out much.”*

The home was also used to create measures of progress and as a way to set and track the amount of activity people felt they could do without exacerbating pain.

P13: *“ I used to Hoover the whole house all the way through. Now just to do a room I have to have a rest after doing a small little room, because that really does my back in, hoovering.”*

Focusing on functional activity in the home for physical activity rehabilitation is a very different approach from the one typically taken by designers of rehabilitation technology. However, it is

the most closely aligned to how people do everyday physical activity and highlights the need for integrating self-directed rehabilitation at home with a focus on functional activity.

The main codes associated with this sub-theme are in Table 8-6.

Table 8-6. Main codes for current sub-theme

Sub-themes	Main codes
Everyday function is rehabilitative exercise	Emotional barriers to exercise: Time, energy, tiredness, lack of routine, lack of feeling of progress/ achievement/ meaning Functional tasks to achieve goals, priority, “need” to be done” Function as exercise: practise stretches, measures of improvement, practise pain management principles. Start at achievable level.

8.2.3 Developing routines and habits can help to maintain activity

Long-term maintenance of physical activity is a challenge for pain management programmes even though they successfully encourage short-term activity gains (Donaldson 2009). One of the strategies that people with CP used for maintenance of physical activity was incorporating activity into everyday routine. In this section we use the term routine in three ways: an exercise routine, a functional activity routine and doing exercise at certain points within a functional routine (e.g., incorporating stretching exercises into routine of cleaning kitchen).

Participants reported that achieving short-term physical activity goals as part of the daily routine added to their feelings of confidence and self-efficacy and increased their (intrinsic) motivation.

P12: *“I have a regular job, with a regular time. So my routine every day is pretty much the same so it becomes an issue of working out a timetable, [...] it's ‘oh when I get up I'll do this, this, this and this and then I'll have 15 min before I have to leave the house and catch the train and in that 15 minutes I should do some stretching. ‘ And when I book that time in I have no excuse not to do it. And I feel better for it.”*

Contrarily, people who do not add physical activity to their routine reported that they did less activity than they would like.

P4 said, *“I sometimes don't get (into) a routine and then I don't do it; I don't do the exercises and then I forget and once I get out of the habit I find it difficult to get back.”*

While an everyday routine could eventually help to make physical activity a habit and reduce the need for planning and motivation, sometimes people did not feel motivated to exercise. In such cases, people reported that adding activity to things they liked to do was motivating and helped them to increase physical activity levels while adding variation and challenge.

P3: *“What I do is I walk to get from A to B or cycle. I might walk with friends, I enjoy chatting, I do Alexander (Technique) work, I lie on the floor; I enjoy a bit of relaxing. “*

P8: *“I like to go around the supermarket because it makes me walk and get out.”*

Some participants reported that doing the same exercises and activities repeatedly was boring and the lack of variation in their exercise routines was demotivating as they did not know how to progress. However, they worried about changing their routine or adding more challenge or demand as they felt that it may cause a flare-up.

P5 said, *“I would like to (vary routine), but I have to be careful, because I do feel limited in what I can do [...] I do the exercises and I feel better, then I don't know what I should do next. I want to do more exercises to maintain but I don't know what I should do because again I worry.”*

Another strategy for adherence to physical activity was committing to doing the activity with another person such as a physical trainer or friend at a specific time, or a physiotherapy session.

P1: *“It's very easy to not do it if you haven't got it pre-booked, pre-planned, and pre-organised [...] if you've got an appointment to see somebody, you can't not turn up.”*

However, for some people planning physical activity away from the home can be challenging based on different factors such as low mood, pain or tiredness.

P11: *“I try to go to a swimming pool and like a hot spa thing around the corner from us. [...] but that depends on, on how well I can actually get there and how tired I am.”*

Technology such as fitness trackers and pedometers is useful for tracking if people are doing a particular amount of activity every day and can be encouraging if people manage to achieve their goals. For example, P10 regularly used a pedometer to track his general activity level.

P10: *“I do use a pedometer and I keep an eye on it during the day because it tells me how active I am or how under-active I am. Like I've only done 2541 steps today so I'm not going to do 10,000 today”*

The main codes associated with this sub-theme are in Table 8-7.

Table 8-7. Main codes for current sub-theme

Sub-themes	Main codes
Developing routines and habits can help to maintain activity	Planning: planning in advance: incorporating exercise into routine, routine, routine based on mood. Introducing variation/ challenge Being accountable Activity outside the home

8.2.4 Rewards, progress and enjoyment of activity are motivating

The previous theme discussed how physiotherapists emphasised the importance of positive feelings in facilitating adherence. In this sub-theme, we discuss how people develop strategies for personal reward and becoming aware of progress.

Setting valued goals and tracking progress towards them is one way to measure progress and increase adherence to physical activity as discussed in Chapter 3. People with CP considered walking a good choice of activity for this aim, as they could track how much they were walking and make small increases gradually.

P1: *“I walk small distances and every day I try to walk a little more”*

People felt that feedback that showed how close they were getting to achieving their goal and what progress they were making would motivate them to stay active and keep trying.

P4: *“It's like a sequence of how you are getting closer to what you aim to do; feedback in the sense of what you have achieved towards something that you want to achieve. Even for more complex movements.”*

Physiotherapists also encouraged people with CP to track progress towards goals that they had set themselves. People with CP also found that progress tracking could be useful for motivation and to prove to themselves that they had been active and making progress.

P1: *“they encouraged us to keep like a chart of our progress so that there was a tangible demonstration of progress, which is very empowering.”*

Seeing progress or improvement that they had made when compared to a previous activity session was also motivating for people. They felt that technology could be useful in tracking and reflecting such progress. In addition to movement, goals and step count, people suggested different measures of progress, such as improved heart rate.

P3: *it could be interesting if it could measure your heart rate for example, how that's different from a month ago. If it could find a measure to say you're getting better.”*

Physiotherapists used psychological measures to assess progress such as increased confidence or reduced anxiety in doing an activity. However, one of the physiotherapists reported that he liked doing gym sessions with participants because they could quite easily see for themselves that they had made progress. While seeing progress was also considered a reward, people felt rewarded for doing activity in different ways.

When asked about what makes them feel good about a physical activity session, most people with CP reported immediate benefit or a sense of achievement. Many said that completing activity or a physical exercise routine was rewarding because they felt better afterwards.

P10: *“if it feels better I'll do it. Very often it's painful to do it but when you lose the stiffness you feel looser. So that's a very definite reward”*

P3: *“I think if I'm doing well I'm breathing better, I feel calmer. Kind of I'm tired in that nice way as well after the exercise”.*

One of the main motivations for people to do physical activity and exercise was to be able to do more things they loved. Some people set themselves extrinsic rewards such as incentives for physical activity to strengthen motivation.

P9: *“I do say to myself that if I can do this then I'll buy something: like if I'm shopping online and I haven't bought something then I think that if I finish this then I'll actually go online and buy whatever it was; yes, I set these small goals.”*

While physiotherapists did not suggest specific incentives or rewards for physical activity, they encouraged people to reflect on what motivated them.

PT2: *“We encourage people to think about what would work for them so we'll mention setting short term goals, acknowledging achievement, giving yourself reward; but we'll just talk about general examples and say to people you know what would work for you.”*

For some people, enjoyment during the activity was important. They reported that they enjoyed listening to music while doing activity and it distracted them from the pain.

P9: *“...just usually music (motivates me) and mostly if I manage to actually complete it (exercise programme) and I can move afterwards and that's kind of a bonus (laughs)”*

Some participants owned game consoles such as the Nintendo Wii and Microsoft Kinect or had played games on these consoles at friends' houses. When asked about what they found motivating in exergames on different platforms, people reported accumulating points and moving up levels. Such incentives introduced fun, engagement and competitiveness in people. However, people felt that in many games, rewards for progress were limited to goal achievement and since progress in CP is so slow they felt that any improvement or progress should be acknowledged by technology.

P11: *“[...] it would be nice to have not just a reward for getting to another level but a reward for improving because it can be very demoralising if you're trying your hardest and have improved but not enough for the next level.”*

People with CP who used exergames felt encouraged when technology gave feedback of real-time progress during a game or while tracking their movements.

P9: *“Sometimes you feel you're not making any progress and if you look at the chart that's being plotted you think ‘right, I'll keep going then.’ Sometimes you can give up heart and if someone shows you that you have made progress, it encourages you.”*

People also felt they would be motivated by seeing progress from a previous time of doing activity.

P8: *“it would be good on that exercise thing if it did plot your limits or what you reached the time before? So you could better it each time.”*

Other people felt that they wanted technology to examine their musculature and suggest exercises based on what it felt were weaker parts. Physiotherapists try to discourage people from thinking in these mechanical terms for improving their pain.

P4: *“for me would be like a perfect bodied person: [...] do a test on how are my muscles or how is my body and then [...] provide exercises to achieve the strength, stamina and the fitness of [...] the perfect person...”*

The main codes associated with this sub-theme are in Table 8-8.

Table 8-8. Main codes for current sub-theme

Sub-themes	Main codes
Rewards and seeing progress are motivating	Rewards: Feel good factor, doing valued activity, seeing progress, better mood; Reminders of positive feelings/ sensations after exercise. Music Track/ visualise progress: activity, physiological measures, movement range, improvement, capability; Comparison with previous activity levels; Feedback visualisation to indicate progress Highlighting achievements: revisiting short term goals Giving positive feedback; reward small movements

In this theme, we addressed strategies adopted and adapted by people with CP to do activity in their everyday lives. The last theme to emerge from our studies was how social alliances with people with CP and with friends or family could help people to be physically active.

8.3 (Re)building social alliances

In our studies, social isolation emerged as a barrier to activity and this is discussed previously in this chapter. However, socialising or exercising with other people, including others with CP,

with friends and family can help people to rebuild physical activity levels. At the end of each sub-theme we present a table listing the main codes related with the sub-theme.

8.3.1 Being active with others with CP increases adherence

All our studies highlighted the importance of social support from other people with CP. Exercise classes are structured and social. People enjoyed the group physical activity sessions run by physiotherapists and there were many regular attendees, in the sessions we observed, who enjoyed interacting with each other. People with CP wanted to attend pain groups or pain exercise sessions because they could relate with others with CP and share pain-related experiences. P10 said,

“So we'd be exercising with other people, you could see the difficulties other people would experience as well ... sometimes you think that the negative experiences with pain that you do have are unique to you to yourself but when you are with other people in a group you realise that's not true.”

Sharing ranged from practical aspects of physical activity to strategies for managing pain. People with CP felt encouraged, understood by others in the group, and reassured by similar experiences faced by others with CP. P12 said,

“I go on a group course. There is a lot of shared experience and you learn what has worked for people and what hasn't.”

Physiotherapists recognised this and designed the pain management programmes to maximise the possibility of socialising and sharing amongst participants by organising group activities. This aspect of pain management programmes was reported as one of the most rewarding.

While motivation to exercise with others with CP could encourage adherence to regular activity, people also found it motivating to see others with CP achieve physical activity goals.

P8: *“the pain management message from the physiotherapist who actually experienced persistent pain herself: I said to myself, ‘if she can do it, I can do it.’”*

CP pain groups on social networks and CP websites with online forums were also popular with people with CP to share tips and strategies. Online social networks provide not only contact and communication with other people with CP, but an outlet for dealing with the emotions of CP.

P12: *“I am in contact on social networks with other people who have chronic pain [...] I get messaged that is encouraging”.*

Interviewees used online social media like Facebook, Twitter or other CP related groups and forums (list in Appendix C.). Other uses of technology included pain websites and also games and apps because people felt quite socially isolated due to pain and technology provided an outlet. Many of these people reported already sharing information about bad pain days, moods, and their condition in general with other people who have CP.

P8: *"It's quite an insular life really coz everything you do is on your own but I do like it (being on social websites) you know and I can talk about my pain and other things that I want to talk about."*

Some people reported that they did not use social media because they felt they were too old or the technology was too complex. They preferred to interact with a *"real person"* rather than spend time understanding or using a technology for physical rehabilitation.

P12: *"I do think that feedback from a real person is always going to be better."*

People who used social forums and groups felt a sense of belonging to a community. They used different means to express themselves and their pain on these forums, such as P11 posted about *"little pain gremlins"* representing her back pain on online social websites. Apart from tips about pain and activity, people also shared their physical activity achievements.

P10: *"I think I might tweet that (achievement) later. "*

People also compared their own pain and activity management to others on pain management groups. These comparisons could be positive or negative for people using these websites. For example, P2 said,

"there's some people that go on the forum and reading what they're saying and you think, 'Oh you silly person! Why don't you do this? (laughs) That's what I'd do.' but we are all different and perhaps I am managing better than I thought I was."

Sharing in groups of individuals with the same problem could lead to getting support and encouragement and feelings of confidence if people felt they were doing better than others in the group. However, some people could get further discouraged if they perceived that other people were managing their pain and activity much better.

Despite pain groups being *"online,"* many were a mixture of online activity and face-to-face activities. This could make it difficult for some participants to feel part of the group if they could not attend the face-to-face activities and these people continued to feel isolated.

P8: *“There is a chronic pain group on Facebook. I follow but they are based in Wales. So they often talk about the group that was just down or the Christmas party so I haven't got that involved with it.”*

The main codes associated with this sub-theme are in Table 8-9.

Table 8-9. Main codes for current sub-theme

Sub-themes	Main codes
Being active with others with CP increases adherence	Social support Sharing experiences, tips Seeing others overcome pain Seeing others with a similar problem; measuring own progress of pain management/ activity against others. Belonging, being part of group Pain forums, online groups give support

8.3.2 Socialising with friends and family reduces loneliness

People with CP can feel isolated from friends and family because of their condition and feelings of being misunderstood or not being able to keep up with others. P11 said,

“I find that if you're achy, it can end up in a pattern of sitting down in a chair or doing the same old things because they are safer, they're not going to cause a flare up. Say if someone comes around and said do you want to go to the cinema, you really want to but if you're achy, you tend to come up with an excuse, to not go.”

However, others felt a lack of support from family, which undermined their condition. They felt that their condition was disregarded or minimised and family did not support them.

FG2P8: *“I haven't got a supportive family and they look at mum [the speaker] and mum looks alright, so mum can do it then can't she. It's only when I suddenly burst into tears or something that they suddenly realise that they have pushed me too far. But I shouldn't have to get to that level where I have to say ‘oh ok I realise I need some help’ because I can't ask for help very easily as I'm used to having to put up and shut up”*

In such cases, technology can help by monitoring psychological states expressed by participants with CP and providing the ability to share with close family or friends how they are feeling or what they are experiencing. Participants felt that sharing such states would enable close friends and family to acknowledge the CP condition or gain better insights into their behaviour.

While some participants felt a lack of support, others reported the opposite: they felt a sense of guilt and avoided enjoyable or leisure activities because they felt that they were not contributing to the house or to work and were a burden on family/ friends.

PT3: *“Sometimes feelings around I shouldn't be doing something like this if I can't do all the housework.”*

One way that people felt supported by family and friends was by making regular commitments to meet for exercising, swimming or walking while socialising. They could also provide practical help to exercise. For example, P7 who lived in a shared flat with a friend, found his help to stretch very useful. She said,

“You can only get so far and you need someone to help, to stretch your arms or stretch your back so you can get further down, so that is really helpful because at home I get so far and then I can't move any further and I need someone (flatmate) to hold the stretch or push the stretch so I can get down a little further.”

However, physiotherapists and people with CP highlighted the risks associated with doing physical activity with people who do not have CP, especially if they were unaware of pain management principles: (i) that people might overdo activity to keep up with activity levels of fitter individuals, or, (ii) that people may compare their level of activity with others and this may affect their confidence.

PT2: *“There's always a risk that by exercising with somebody else, they may overdo things, they might feel inadequate that they can't keep up.”*

P1: *“Say if I was in a group of able-bodied individuals, I was often risking my own health by overdoing it because I felt the need to do the same as everybody else.”*

Some of the people with CP would have liked to share their achievements online with their own friends who did not have CP. However, they thought that their “able-bodied”(P3, P7) friends would not be interested or even understand their achievements (e.g., P5, P12, P3, P7), as they do not have the same physical limitations.

P5: *“I probably would like to but a lot of them are not interested.”*

Many people with CP wanted to play movement games (exergames) socially with family and friends who did not have CP and suggested making games low impact and also starting from a very low level and building up so people with limited mobility could participate. P11 enjoyed playing Kinect games despite having CP and had various suggestions for improvement such as modifying the games for use by people with CP by making them more accessible and slower paced.

P11: “we have quite a few Kinect games and there was a Tai Chi Kinect game that was quite good and fun to try. [...] balance blocks, I liked that because I could play that with others.”

P11: “they (Kinect) have got games that you can do with your arms and they all seem to work with you standing up but there's no reason why they shouldn't work with you sitting down. [...] So those games that are not all about jumping up and down and it's too much for someone who's in pain.”

P11: A lot of the games at the moment are about speed, [...] have a game that has bubbles and you've got to pop the bubbles because you can do that slowly but it could still be a game that you could play with someone else and would make you move.”

People who had played on the Kinect and Wii had favourite games that they thought would be useful and engaging.

P8: “Something like, you know, a Wii game, I don't know if they're any out yet but the dance one I would use and that would sort of make me move and stretch anyway. And if they came out with a medical one, I would definitely get one for CP, definitely.”

However, most people with CP interviewed by us did not feel they would use such games to exercise and had reservations about their usefulness; they perceived these games as a frivolous activity rather than serious exercise. They also felt that placing a movement games console with the TV in the living room would affect the rest of the family, which meant that they would feel “embarrassed and awkward” (P3, P4) playing the games in front of their fitter or younger family members and might also cause inconvenience to others in their homes. For example, P1 said, “I know it (Wii) is very popular, I know that the health things on it can be very beneficial. I just feel ridiculous, standing in my own living room doing it”

Some participants also felt that the use of movement games for exercise could stop them going out for drop-in and group classes leading to even more social isolation. P3: “I don't play videogames. I don't want to spend my time looking at a screen.” The main codes associated with this sub-theme are in Table 8-9.

Table 8-10. Main codes for current sub-theme

Sub-themes	Main codes
Socialising with friends and family reduces loneliness	Trying to keep up with others Social support Guilt Feeling overwhelmed Embarrassment Use of technology to detect psychological states

8.4 Discussion

This chapter presented the findings from various qualitative studies to investigate needs and barriers faced by people with CP when doing physical activity and strategies they may apply to address them with the aim of informing the design of physical rehabilitation technology. A dual perspective was explored: people with CP who are learning to self-manage their condition and physiotherapists with expert knowledge and experience to support them. In this section, we discuss four of the important points that emerged from this work.

8.4.1 Focusing on pleasure and positives not pain

Many people reported that pain interferes with activities and they felt that doing the activity was not worth the pain. Physiotherapists directed the focus away from pain and negative emotional states to normal and pleasurable sensations like breathing and normalised body sensations due to stretching/ exercising a body part after a prolonged period of time. Our findings show that the type and quantity of feedback provided by physiotherapists is based on the psychological state of the patient and on where s/he is in the journey. Analogously, technology could be tailored to respond, for example, to confident steady performance of a previously feared movement with encouragement to try a small increase or a more complex version of the same exercise. Anxiety when performing a movement could instead be met by a reminder about breathing, as suggested by physiotherapists. Gromala et al. (2011) used a VR chamber for a meditative walk designed to address anxiety in people with CP but this was not based on a movement that is feared and was in the presence of a physiotherapist at a clinic.

8.4.2 Facilitating a sense of control and confidence

While people are able to do exercise or activity in the presence of a physiotherapist as they feel reassured and the physiotherapist is in control and directing rehabilitation, they find it difficult to extend these gains into everyday exercise and function on their own. Our findings suggest that any technology for CP, as in other chronic illness (Mynatt et al. 2010) should enable the person to take control and assume responsibility for progress. Our findings also highlight that there is a need for adequate support and reassurance with respect to physical activity, such as that provided by the physiotherapists in the beginning of the journey.

Rehabilitation technologies for CP (e.g., Schönauer et al. 2011) show the potential for providing engagement and motivation for activity, but are not designed to address the psychological factors associated with physical activity in CP (Turk & Okifuji 2002). They rely on the presence (co-located or at distance) of a physiotherapist to address possible psychological needs and to

set the parameters and targets for the activity. Physiotherapist presence is appropriate for clinical rehabilitation but needs a rethink for self-management in CP, where experience of activity exacerbating pain and even leading to serious setbacks (Harding & Williams 1995) generates overcautiousness, and concern to establish a 'safe' amount of activity. Such technology design also limits opportunities for providing skills for learning self-management of activity and for transferring of gains from exercise to functional activity.

Duggan et al.'s (2015) SMART2 system allowed users to collaboratively set goals with a researcher. It could then be used in the home, independently of the physiotherapist, to track steps during an activity and give people feedback about their overall activity levels. While this technology is a step in the right direction for improving overall activity levels, it does not address other movements during an activity and the psychological factors associated with avoidance of certain activities. It also requires that the clinician is present when new targets need to be set.

In our findings, physiotherapists' main role was mainly to provide the skills and tools to identify beneficial movement and ways of achieving it. In this context, our results suggest that technology should act as a facilitator and provide a space to shape and learn skills and gain confidence in managing physical activity needs. To achieve this and to transfer responsibility from the coach (technology or clinician) to people with CP, the latter should have a role in designing and defining the exercise space. As Johnson et al (2013) suggest, by being in charge of calibrating their own movement space, people can build an understanding of what these spaces mean and hence can better appropriate them to address their physical and psychological needs. However, the current design of the SMART2 system (Duggan et al. 2015) requires clinicians or researchers to do so, limiting the space for learning self-management skills.

The role of technology as facilitator is contrary to the typical approach of designing technology for physical rehabilitation (Geurts et al. 2011), which focuses on instruction, correcting movement and providing targets on the basis of physical performance. Physical rehabilitation technologies such as RehabMaster (Shin et al. 2014) and mini games developed for stroke, discussed in chapter 4, work on very small focused movements such as finger flexion and extension (Alankus et al. 2010) with very precise instructions. People move within a target range to improve movement within that range and physiotherapists and clinicians define the range or goal for movement. Further, unlike for people with CP, correcting movements is important for patients of stroke, as wrong movements can be harmful.

Commercially available exergames either focus on structured exercise and correction of movement or they are too demanding for people with CP as evidenced by our interview

findings. Correction of movement is discouraged by physiotherapists especially in the early stages of the journey where the aim is to start moving; physiotherapists also emphasised that most of the time it was about building confidence and self-efficacy in movement and correcting people can undermine this because they would always question if they are doing it correctly.

While correction is not an important goal for physiotherapists, *facilitating a sense of control* through building awareness of body sensations and activity is considered very important. According to our findings, if people rely on pain as an indicator, they may overdo activity or overtire themselves before they feel the pain. People also need to be aware of their current capabilities and limits to build on them. These capabilities are physical as well as psychological: in the beginning of the journey, when setting baselines, it is not about how much people can stretch physically but also how much stretch they feel *comfortable and confident* in performing. Exploring these capabilities and limits build an understanding that people can work to build levels of physical ability without exacerbating their pain and therefore work to promote self-directed activity rather than exercise only in the presence of physiotherapists.

8.4.3 Increasing awareness and rewarding effort

In our findings, important strategies that emerged included awareness of and exploration of movement to understand one's physical and emotional capabilities. Hence, rather than correcting movement and focusing on targets, the focus shifted to performing the movement with confidence and listening to body cues. The question is how can technology take on this role of compensating or substituting a proprioceptive system that is altered by emotional factors and attention to pain.

While technology has been used to allow people to explore their individual capability, this use has been restricted. Commercially available movement games allow people to choose levels according to their capability, such as easy, intermediate and difficult but capability in people with CP may be much more fine-grained than for the general population. At times people with CP may be unaware of doing small movements because of a restricted movement range so working to get to the next level in a game may be very frustrating. The need from technology for people with CP is to reward even very small movements so that people become aware of the movements they perform and build confidence. Technology can be used to detect small movements that people do and give them feedback that enhances awareness of movement and increases confidence. In addition, sensors can be used to detect the appearance of protective behaviour and its automaticity and increase awareness.

Goals need to be set that are the right level of difficulty for physical and psychological capability, so that they pose a challenge but are not too difficult to be demotivating as proposed by the flow theory discussed in chapter 4 (Csikszentmihalyi & Csikszentmihalyi 1992). Other principles of gamification can be used to set rewards for achievement of big and small goals and giving constant feedback rather than feedback only on achievement of goals). Current exergames developed for CP (Schönauer et al. 2011) also use goal setting and constant feedback but goals, targets and the level of challenge is discussed and set by physiotherapists rather than by people with CP themselves. This is contrary to behaviour change theory and findings in persuasive technologies such as *Ubifit*, where goals are most effective when the person sets them him/herself (Consolvo et al. 2009).

Achieving personal functional goals is important and technology could aim to be able to represent activity completed as progress towards goals. More complex goals may need to be broken down into individual activities and people's progress on each of the component activities could be tracked to form an overall picture of the goals they want to achieve. Schonaeur et al.'s (2011) recommendation of using mini-games for this aim is useful as they suggest the means to improve, for instance, movement range, but this needs to be linked to goals that users have in daily life that the increased movement can help them achieve.

8.4.4 What is progress?

As our findings have shown, progress in CP is not just physical but it is psychological. However, this is very different from the current rehabilitation technology design for CP, which still focuses mainly on physical gains (e.g., Jansen-Kosterink et al. 2013).

Further, progress in CP is slow and therefore feedback on progress needs to handle a slow pace and discouraging, though temporary, setbacks (Harding & Williams 1995). The concept of *pain management journey* in technology design could be useful to define targets and measures of self-management skills. The *journey* shifts the focus from physical skills to people's needs and how these vary along the journey: at the start, the goal may be to recover confidence in movement and to do it with less anxiety; later the focus may be to increase the amount or effectiveness of movement to achieve a goal. A measure of progress should recognise that it may be slow and setbacks are likely: during these, capabilities are reduced and expectations may need to be adjusted.

A sense of achievement is provided not only by displaying cumulative change but also by offering alternatives, promoting awareness of movement and of pleasurable sensations, and helping to prevent overactivity that leads to setbacks. This builds confidence in activity and

bolsters motivation and self-efficacy. Also, our findings suggest that pain is a poor indicator of pacing activity and often when people measure how much activity they should be doing by their pain levels, they may find that the pain level can change quicker than they anticipated and they overdo activity before they realise it.

Our first studies have brought to light many interesting strategies that could be implemented and even extended with the use of technology to address the psychological barriers to physical rehabilitation. In the next part we will bring emotions and affective states at the centre of design for rehabilitation in CP by implementing and empowering some of the strategies that emerged from this study through the use of sensing and feedback technology. We will focus on the use of sound to empower these strategies.

Part II

“Empowering”

Chapter 9: *Go-with-the-Flow*: Tracking, Analysis and Sonification of Movement and Breathing to Build Confidence in Activity.

Chapter 10: Evaluation of the *Go-with-the-flow* framework.

Chapters in this part have been published in HCI 2016:

*Singh, A., Piana, S., Pollarolo, D., Volpe, G., Varni, G., Tajadura-Jimenez, A., Williams, A.C., Camurri, A. and Bianchi-Berthouze, N., 2016. **Go-with-the-flow: Tracking, Analysis and Sonification of Movement and Breathing to Build Confidence in Activity Despite Chronic Pain.** Human–Computer Interaction, pp.1-49*.*

*Roles for each author are overleaf.

*Roles of each author.

Singh, A. designed the sonification framework and wearable device and ran all the studies. She led the writing of the paper. The Kinect-based technology was based on the sonification-framework designed within this thesis.

Piana, S., Pollarolo, D., Volpe, G., Varni, G, Camurri, A.: Built the Kinect sonifications based on our sonification framework. (Referred to as University of Genoa in the following chapter).

Tajadura-Jimenez, A.: Advised on embodiment and sound.

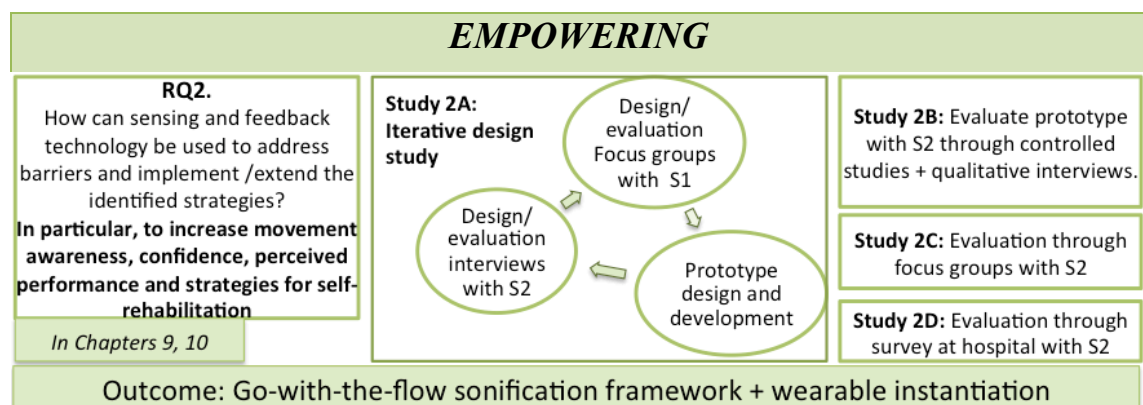
Bianchi-Berthouze, N. and Williams, A. are supervisors for this thesis and advised on the research as well as writing the paper.

Chapter 9 *Go-with-the-Flow*: Tracking, Analysis and Sonification of Movement and Breathing to Build Confidence in Activity

In the previous chapters (Part 1) studies with people with CP and physiotherapists were run to get an understanding of their barriers, needs and strategies from physical activity self-management technology. The concept of a journey emerged in the previous chapter, with different phases: exploration, building and maintenance. Initially, when starting the pain management journey, exploration and building are important. We focussed on these two initial phases to design a technology for people with CP to engage with physical activity.

Within the emotional aspects, we focussed on fear of movement, lack of self-awareness of movement, low confidence in performing movement and pessimism about low worth of doing movement due to high cost of pain. These emerged as the most important affective barriers to physical activity in our study. What also emerged from our studies was a set of strategies tailored towards increasing a sense of control within people with CP and adapting this control through strategies people developed in their own lives. For example, enhancing movement awareness by directing attention to it and focusing on pleasurable sensations such as breathing. We used all these findings to ground our approach to design of technology to empower these strategies in the absence of a physiotherapist. By doing so, we investigate the second research question of this thesis. An overview of the studies carried out in this chapter is in Table 9-1.

Table 9-1. Research question and studies for Part 2: “Empowering”. The first study was an iterative design study, followed by controlled studies, a focus group study and a survey at a hospital in that order. S1 is used to refer to physiotherapists while S2 refers to people with CP in the figure.



To address the research question, we proposed a framework for technology with the aim to rethink technology for physical activity support in CP rehabilitation. The focus was to move away from simply reusing technology designed to motivate physical activity for the general population or other chronic conditions as discussed in Chapter 4, because psychological and emotional states in CP can interfere with physical activity regardless of the person's capability or level of pain. We approached the problem by exploring the use of sound feedback on movement; sound is proposed as the feedback modality to design exercise spaces within which people may feel confident in exploring and exercising for several reasons:

- Recent work in CP (Cepeda et al. 2006) and technology design for CP (Vidyarthi et al. 2012) showed that sound feedback can facilitate introspection and is effective in reducing anxiety. Aural feedback can be used to improve perception and awareness of a body function (e.g., breathing) and has been used in studies to teach mindfulness skills (Vidyarthi et al. 2012).
- Unlike visual feedback, which requires focusing on a display, aural feedback does not need fixation on a display, and so it is more compatible with natural movement.
- Finally, sound has been shown to have positive effects in motor rehabilitation (e.g., Rosati et al. 2013; Vogt et al. 2009), such as initiating movement, facilitating coordination and improving performance. One of the aims, specific to CP, is using sound to shift attention from a feared aspect of movement to a pleasurable and informative signal, increasing awareness of movement to counter altered perception (Lee et al. 2010). The reason for this is an emphasis on fostering control, setting achievable targets and facilitating progress, as our findings indicate these are important in encouraging people to participate in a programme of physical activity.

The rest of this chapter is organised as follows: in the next section, we present the literature on the use of sound and sonification to facilitate body awareness, motor learning and positive experience. We then present the Go-with-the-flow framework and iterative design study to design and develop a wearable instantiation of the framework with physiotherapists and people with CP. Next, we present controlled studies and qualitative studies (including focus group and diary study) to evaluate the framework. Finally, we discuss the implications of the framework and next steps. The Go-with-the-flow framework is one of the contributions of this thesis.

9.1 Sonification to represent, understand and motivate body movement

Neuroscience research has shown that our brains use all available sensory feedback, including sound, to keep track of the changing structure and position of the body in space (Botvinick & Cohen, 1998; De Vignemont, Ehrsson, & Haggard, 2005) and to adjust actions (Wolpert &

Ghahramani, 2000). For instance, the sound of tapping with an object on one's hand provides information about hand position, arm length (Tajadura-Jiménez et al., 2012) and force applied (Tajadura-Jiménez, Furfaro, Bianchi-Berthouze, & Bevilacqua, in press), or the timing of steps when walking (Menzer et al., 2010). Using this information, the individual can adjust movements. This relation between sound and movement is supported by tight links between auditory and motor areas of the brain. For instance, listening to rhythms activates motor and pre-motor cortical areas (Bengtsson et al., 2009; Peretz & Zatorre, 2005), hence the use of rhythmic acoustic feedback to entrain movement (Kenyon & Thaut, 2005). In addition, natural (e.g., Bradley & Lang, 1999) or artificial sounds such as tones and music have been shown to trigger emotional responses in listeners. Studies on the human brain have shown unlearned preference for certain types of sound, such as harmonic and periodic sounds (Lenti Boero & Bottoni, 2008), of which music is a particular case (Juslin & Västfjäll, 2008; for overview see Juslin & Sloboda, 2001). This growing body of work supports the use of sonification of movement and related processes as a powerful way to increase positive body awareness in CP and facilitate engagement with movement.

Sonification has been investigated as a scientific method to facilitate understanding of complex information. The most recent and complete definition of sonification is “data-dependent generation of sound, if the transformation is systematic, objective and reproducible, so that it can be used as scientific method” (Hermann, 2008). Dubus and Bresin (2013) provide a recent survey on sonification, and general design guidelines, across different research fields. Interactive sonification - “the use of sound within a tightly closed human-computer interface where the auditory signal provides information about data under analysis, or about the interaction itself, which is useful for refining the activity” (Hermann, 2005) offers real-time interaction between an individual and an auditory display.

Whereas sonification consists of a systematic mapping of data streams onto specific sound features, active music listening provides users with ways of intervening on the music content they are listening to to change and mould it according to their wishes, intentions, or aesthetic preferences. In early work on active music listening, Camurri (1995) and Goto (2007) proposed a content-centric system for intervening on pre-recorded music with signal processing techniques to select sections, skip, and navigate parts of the recording. More recently, Volpe and Camurri (2011) and Varni et al. (2011) developed active music listening applications controlled by full-body movement and expressive gesture; they showed that alteration of music through body movements resulted in convergence of peoples' movements, thus showing an effect in driving movement behaviour.

Indeed, sonification of body movement, as a means to inform, has been shown to improve motor control and possibly motor learning (Effenberg, 2005; Effenberg, Fehse, & Weber, 2011; Effenberg, Weber, Mattes, Fehse, & Mechling, 2007) in sports training studies (golf swing: Kleiman-Weiner & Berger, 2006; interactions within a sports team: Höner, Hermann, & Grunow, 2004; rowing: Dubus, 2012, and Schaffert, Mattes, & Effenberg, 2010; aerobics for visually impaired people: Hermann et Zehe, 2011; skier's centre of gravity Hasegawa, Ishijima, Kato, Mitake, & Sato, 2012). In fact, according to Hermann's definition of sonification, using music material may not fully comply with the requirements that sonification should be systematic, objective, and reproducible. However, Varni and colleagues (2011) showed that the mapping of data on high-level properties of music such as tempo, articulation, timbre, and so on can be used for sonification if its goal is not purely aesthetic, but rather consists of improving the understanding or the communication of information about the original data domain, referred to as active music listening.

Sonification is not new in physical rehabilitation either. It has been shown that sequences of tonal beeps can facilitate robotic-assisted movement training after stroke or spinal cord injury (Rosati, Rodà, Avanzini, & Masiero, 2013; Wellner, Schaufelberger, & Riener, 2007); sonification of electromyographic data during rehabilitation can guide the person towards a target movement (Pauletto & Hunt, 2006); PhysioSonic (Vogt, Pirrò, Kobenz, Höldrich, & Eckel, 2009) transforms 3D movement analysis of shoulder joint kinematics into audio feedback to correct posture or coordinate a therapeutic exercise; this type of sonification can help coordination in patients with poor proprioception (Chez, Rikakis, Dubois, & Cook, 2000; Matsubara, Kadone, Iguchi, Terasawa, & Suzuki, 2013), a relevant problem for some people with CP (Lee, Cholewicki, Reeves, Zazulak, & Mysliwiec, 2010). In all these studies, sonification appears to be a powerful way to tap into body perception and also to enhance the perception of movement in rehabilitation though its main use has been to improve performance. Here, we investigate how it can be designed to address the barriers identified in Chapter 7 by implementing, extending and empowering strategies identified in Chapter 8.

In sports and physical rehabilitation contexts, variables describing the movement are mapped into sounds to enhance the perception of the quality of the movement or its deviation from a particular model. Metaphors are used to facilitate the mapping between movement qualities and sound. Music is however not generally used unless for aesthetic or relaxation purposes (Gromala et al., 2015; Vidyarthi & Riecke, 2013; Nazemi, Mobini, Kinnear & Gromala, 2013).

Building on this body of work, in the next sections we present our sonification framework to overcome the psychological barriers that people face by implementing and empowering the

strategies identified in the previous chapter. Two main studies were carried out. The first is an iterative design study to design the sonification framework and the body-sensing devices to explore it. The second study makes use of instantiations of the sonification framework to evaluate its effectiveness and better understand how people with CP may appropriate it. All studies have National Health Service (NHS) and University College London (UCL) ethics approval and were conducted in accordance with ethics guidelines.

9.2 Design study: sonification framework and sensing devices

The aim of this design study was to create the Go-With-the-Flow sonification framework for defining Sonified Exercise Spaces (SEs), within which people are aware of their body and feel confident in moving and can gradually build their psychological and physical capabilities. The framework evolved through iterative revisions that were instantiated into prototypes (body tracking and sonifying devices) for discussing and exploring concepts with physiotherapists and people with CP. The research questions that we aimed to address in this study were:

1. *Can sound be used to support physical activity in people with chronic pain?*
2. *Can sound be used to facilitate learning of self-management skills?*
3. *What pain management principles must be encapsulated in the auditory feedback to make it effective for use in physical activity sessions?*
4. *How should the principles be translated into sonification elements?*

Four iterative focus group sessions were run to elicit views of pain management specialist physiotherapists and people with CP. During each iteration, a new version of the body tracking and sonifying device was presented to provide examples of SEs that reflected the revised framework. Three physiotherapists from the University College London Hospitals trained in cognitive behavioural therapy (CBT), each with more than 6-years of experience in pain management participated in the focus groups.



Figure 9-1: (Middle) Device attached to the back for sonifying trunk movement during the forward reach exercise (Left). (Right) Examples of SEs for a forward reach exercise: the Flat sound is a repetition of the same tone played between the starting standing position and the maximum stretching position. The Wave sound is a combination of two tone scales (phrases), an ascending one ending at the easier stretching target and a descending one to the final more challenging target. The reaching of the easier target is marked by the highest tone.

For brevity, we first present the framework that emerged at the end of this iterative design study. Then we report the findings from the iterative focus group studies. Lastly, we describe the final design of the devices, informed by the iterative focus groups. In the following chapter, we present the final three studies (quantitative and qualitative) to evaluate it.

9.2.1 Go-With-the-Flow Framework

The *Go-with-the-Flow* framework consists of three parts: i) Design principles for Sonified Exercise Spaces (SESSs) derived from strategies that physiotherapists and people with CP use to facilitate physical activity; ii) sonification paradigms and elements that implement the principles and are combined to create SESSs; and iii) sonification alteration methods to increase awareness of use of avoidance or protective strategies. These three parts are described in Boxes 1-3 respectively. The framework evolved through exploration with physiotherapists and was based on previous literature on sound discussed in Section 2. Figure 9-1 shows a wearable sensing and sonifying prototype and two examples of SESSs built with this framework.

BOX 1	<i>Go-with-the-Flow</i> Framework – Part 1
	SES DESIGN PRINCIPLES
<p>Principle 1: Provide an enhanced perception of moving through sonification that provides an enhanced and pleasurable perception of movement, particularly when i) movements are restricted and perceived as not worth attempting; or ii) anxiety is high and attention is on pain.</p>	
<p>Principle 2: Provide a sense of progress through movement to increase self-efficacy. Different sonification assigned to different phases of an exercise can address varied barriers and needs.</p>	
<p>Principle 3: Facilitate <i>going-with-the-flow</i> by reducing the need for continuous monitoring (to free cognitive resources); the sonification should represent the body in space (e.g. by targets reached).</p>	
<p>Principle 4: Provide sense of achievement and reward through the use of specific sonification to mark target attainment. We refer to these specific targets as anchor points.</p>	
<p>Principle 5: Increase awareness of avoidance through alteration of sonification, in a way easy to understand and which encourages movement exploration. To avoid increasing anxiety or beliefs about threat, the signal should not be perceived as indicating wrong movement or danger</p>	
<p>Principle 6: Encourage preparatory movements (e.g., bending forward before standing up</p>	

in a sit-to-stand movement) by using different sonifications from those used for the exercise which have been avoided (due to fear of increased pain or automaticity) but in fact facilitate normal movement.

Principle 7: Develop self-management skills by tailoring sonification to the appropriate level of pacing for the person's physical and psychological capabilities and current pain level can help to: 1) discover physical capabilities and psychological needs; 2) learn to tailor activity to physical and psychological resources; 3) perceive progress and gradually build capabilities.

Principle 8: Underdoing vs. overdoing: SES boundaries should be designed to encourage movement but not overactivity with a risk of setbacks.

BOX 2	<i>Go-with-the-Flow</i> Framework – Part 2
	SES SONIFICATION PARADIGMS AND ELEMENTS
<p>Simple tone: This is the simplest sound content that can be played at different pitches. The use of simple tones enhances the perception of each unit of movement (Principle 1).</p> <p>Sonic phrase paradigm: A set of correlated sonic events characterised by variations (discrete or continuous) of one or more sonic features can be used to provide a sense of progress (Principle 2). For example, discrete pitch in a tone scale; or timbre (e.g., from dark to bright) in a rich spectral sound.</p> <p>Combination of phrases: Different phrases can be used to sonify different parts of a movement to further enhance progress through it (Principle 2). For example, an ascending scale of tones can be a metaphor to highlight a sense of progressing towards a desired achievement, whereas a descending scale can be used to provide a sense of progressing towards the ending of a difficult movement.</p> <p>Anchor points and SES boundaries: Endings of phrases, changing between consecutive phrases, or other clearly identifiable sounds can be used to mark milestones and targets to enhance achievements (Principle 3), facilitate awareness of body position (Principle 4) and signal boundaries of SESs to reduce hypervigilance (Principle 4). Movement beyond the boundaries of the SES may be sonified to encourage building capabilities (Principle 8).</p> <p>Naturalistic sound: a sound simulating or evoking everyday life sound objects or sounds of living beings, usually characterised by continuously varying time-frequency model over time: from simple white noise (wind-like sound) to complex sounds resulting from a set of equations and algorithms simulating a physical source of sound (Rocchesso, Bresin &</p>	

Fernstrom, 2003). Naturalistic sounds can be more relaxing and preferable in longer sessions (Principle 1), since they cause less fatigue in the auditory system due to the continuously varying time-frequency features. The use of single naturalistic sound can be used to enhance the perception of each unit of movement (Principle 1).

Self-Calibration: the definition of the SES (selection, combination and tuning of sonification elements) should be carried out by the person through exploration to facilitate understanding of physical and psychological capabilities and progress (Principle 7). The calibration should be re-adjusted as needed including setbacks and bad days (Principle 8).

BOX 3	<i>Go-with-the-Flow</i> Framework – Part 3
	SES SONIFICATION ALTERATIONS
<p>Alterations of the sonification should encourage exploration of movement capabilities rather than provide a sense of danger or “wrong” (vs. correct) movement. The alterations investigated are:</p> <p>Use of lateral protective movements: altering the sound in a way that highlights the body part where the movement is avoided. For example, if a person avoids using one part of the body during a symmetric movement, sound is played only on the opposite side (e.g., the ear corresponding to the part of the body that is used). This should induce exploration of the avoided body part to recover lost sound.</p> <p>Use of protective movements (either backward or forward) to avoid shift of centre of body mass: shifting the tone scale to a lower or a higher octave (without distortion). For example, during a forward reach exercise, the pelvis may be pushed backward while moving the trunk forward to keep the centre of body mass aligned with the feet.</p> <p>Avoidance of preparatory movements: The sonification associated with the preparatory movement is not played or not fully played, and the subsequent sonification of the exercise itself is distorted. This alteration aims to convey the feeling of not have gained sufficient energy to complete the movement.</p> <p>Fast pacing to avoid engaging with the movement: Sound volume decreases when the movement is performed too fast to increase awareness of pace and encourage slowing down. A decrease rather than an increase in volume was proposed as an increase in volume could either reinforce arousal and reward speed or lead to increased anxiety as it may signify alarm.</p> <p>Shallow breathing: breathing sounds are produced over the movement sonification to invite breathing.</p>	

9.2.2 Iterative evaluation with physiotherapists and people with CP

The sonification framework was implemented through sensing devices that tracked and sonified body movement and breathing patterns of a person in real-time; one of the devices was wearable and the second was Kinect-based. The framework and the devices were iteratively tested and refined through four focus groups. The focus groups were audio- and video-recorded and transcribed data was analysed using thematic analysis (Braun & Clarke, 2006). Emergent themes are described below. The final version of the devices is presented in Section 9.3 .

Engagement, awareness and reward

Physiotherapists found the use of sonification feedback motivating and informative. They particularly commended the possibility of calibrating the sonified exercise space to each individual. They thought people with CP would find the feedback engaging and anticipated its use not only to facilitate practicing movements, but also to encourage movement exploration, which is an important aspect both in the initial phases of the pain management journey and later in adapting to daily needs as discussed in the previous chapter. Initially when building physical and psychological capabilities, people need to explore what their body can do without overdoing; on bad days and during setbacks, people need to adjust their targets to avoid pain exacerbation. Physiotherapists also felt that the device would be particularly rewarding for very restricted movements, which are often demotivating as people do not value performing them and may even be unaware of doing them. Thus, tailoring the exercise space to the person's capabilities using the device could enable tailoring rewards to ability, rewarding even small movements to enhancing awareness of and motivation in performing them. Physiotherapists thought that discrete steps in sound could provide a sense of progress that could be lost in continuous sound especially when movements are constrained, e.g., a very limited bending of the trunk. When discussing boundaries of SESs, they were critical of what they perceived as the technology signalling a “safe” zone for exercise, as that implied an “unsafe” zone beyond, reinforcing an unhelpful model of pain as warning of damage. Instead, they emphasised that small increments and regular physical activity would build confidence in movement. They also expressed concern that focus on a target could distract from quality of movement and encourage strain or lead to disappointment about underperformance when the target was not met. Physiotherapists also wanted the sonification to continue after the maximum target, as they felt stopping the sonification at this point was like *“punishing people for trying harder”* .

What to track beyond movement

From the first iteration, physiotherapists suggested that the device could target other pleasurable sensations for body awareness such as breathing. Since breathing rate rises with anxiety, and patients often hold their breath if they are anxious or overly focused on a movement, physiotherapists suggested calibrating the breathing depending on (i) apical vs abdominal breathing and (ii) the number of breaths per minute in a relaxed state, using superimposed breathing sounds as a prompt to breathe calmly. Physiotherapists also commented on the features for increasing awareness about protective movement by altering the sonification. For example, when the person leaned more to the left, the sound was louder in the left ear. Physiotherapists liked this feature as it informed without being corrective or prescriptive and emphasised that this alteration should not be designed in such a way that it was perceived as an indicator of “*wrong movement*”. On the possibility of providing muscle activity feedback, physiotherapists were concerned that this could generate anxiety about doing movements “*wrong*” or in a “*damaging*” way; this would be contrary to their message of “*moving little and often*” to build activity rather than moving “*correctly*”.

Shifting from physiotherapist-driven to patient-driven activity

The use of the device to teach self-management skills was also discussed. Physiotherapists thought that their patients would “*love exploring their movement with the sound*”, especially those with limited movement. Thus, the device could function as a bridge between clinic and home during the pain management programmes run by hospitals (about 6 weeks long). When anxiety about a particular movement was high, physiotherapists typically set a modest baseline, which could be set using the device, and the sound feedback used to reward people for movement and provide reassurance, thus enabling people to explore and practice movements at home. Finally, physiotherapists felt that they could use the device with patients to explore other body cues that could be used to tailor daily exercise. Physiotherapists often suggest cues to be used for facilitating movement as discussed in Chapter 7. For example, it may be useful to bend forward or look down while doing certain activities to make it easier (not “*safer*” or “*correct*”) and sound feedback could be used to trigger such preparatory movements. They suggested that the device could reinforce doing the movement as the goal and not just reaching a certain target.

9.3 Devices design

Two versions of the Go-with-the-flow device were developed to explore both the advantages of mobile wearable tracking devices and of full-body tracking systems. The wearable device (Figure 9-1(Left): initial prototype; Figure 9-2: final prototype) used a smartphone for tracking

a part of the body while investigating different sonification options for transfer from exercise (e.g., forward reach) to everyday functioning (e.g., forward reaching to a shelf).

9.3.1 Wearable device

The wearable device (Figure 9-2) is formed of an Android Google Nexus 5 smartphone and two respiration sensors. The smartphone sensors are used to detect the amount of bending of a particular part of the body where the smartphone is worn (e.g., of the trunk). Two respiration sensors (Mancini et al., 2014), one to measure diaphragmatic (abdominal) breathing and the second for apical breathing (Figure 9-2a-b) were designed to measure lung volume, and hence respiration, through the proxy of thoracic and/or abdominal circumference. Each respiration sensor consists of a band with a stretchy section made of conductive material, expansions and contractions of which cause a change in voltage that is detected by the Arduino-based breathing sensing device. A tabard, of adjustable girth and to be worn over existing clothes, was designed with a transparent back pocket for the smartphone and velcro loops on the front to keep the breathing sensors in place (Figure 9-2-c). The breathing device was placed in a laser-cut acrylic case that was put in the back pocket of the tabard (Figure 9-2-c). A smartphone was used to track, sonify and store information about movement of the body part where the smartphone was worn. A simple visual interface was designed with a choice of sonification options (Figure 9-2-d) to allow selection of the sonification to be investigated within each experiment and to monitor the data collection. Since the smartphone could be worn on any body part (e.g. on the trunk (Figure 9-2-c)), a button connected via a wire to the Arduino module was added to facilitate the calibration process.

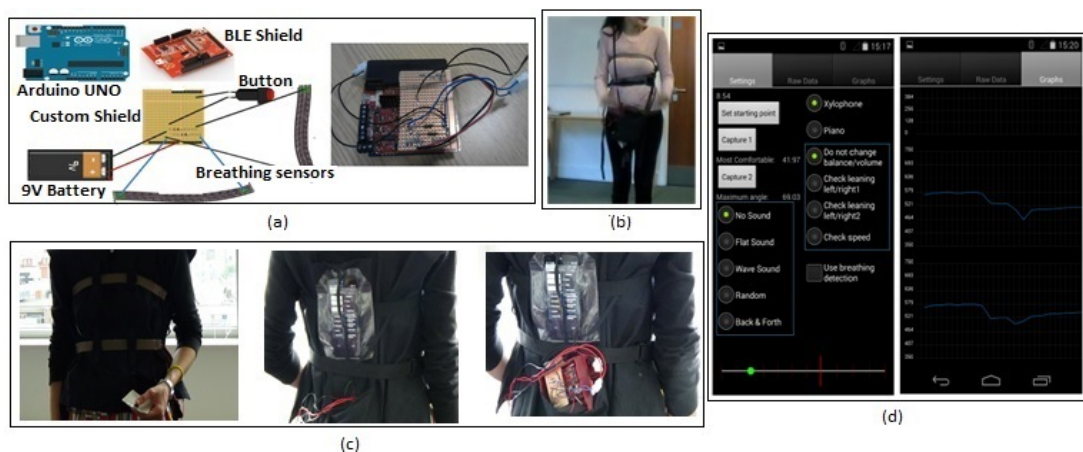


Figure 9-2: Final design of the wearable device: (a) Architecture of the breathing module built using Arduino UNO. (b) Breathing sensors. (c) Front and back views of the tabard with integrated breathing sensors, button held in the person's hand for calibration, the smartphone in its pocket on the back of the trunk and the breathing sensing module shown outside its corresponding pocket. (d) Smartphone interface for selecting SESS and visualization of the tracked signals.

After initial testing of the wearable device, the second system used the Microsoft Kinect and was developed in collaboration with University of Genoa to track the full body and was developed to explore not only our existing sonification paradigms but also two more complex ones that were added by University of Genoa as an extension of the sonification paradigms presented in Box 2 (see below).

Extension of BOX 2 (By University of Genoa)	<i>Go-with-the-Flow</i> Framework – Part 2 (Extension)
	SES SONIFICATION PARADIGMS AND ELEMENTS
	<p>Soundscape paradigm: a (possibly non-linear) structured composition of naturalistic sounds, inspired by electroacoustic music (e.g., Berry Truax) and sound synthesis techniques (e.g., granular synthesis). A soundscape can provide a sense of progress through a movement, (e.g., feeling of approaching a sound source (Principle 2)), facilitate <i>going-with-the-flow</i> by inducing relaxation (Principle 3), and provide a sense of achievement (e.g., feeling of arriving at a sound source (Principle 4)).</p> <p>Active listening paradigm: an extension of interactive sonification based on the real-time interactive manipulation and moulding of (possibly personalised) pre-recorded music content. Interactive manipulation includes interventions on the orchestration, e.g., the continuous control of the single voices and instruments forming a music piece, and the control and manipulation of timbral and rhythmic features. The manipulation of a known music piece may link to personal experience in the subject, and may thus contribute to stronger participation and engagement in sonification (Principles 1 and 4). Thus through the movement, the person engages in simulating creative mixing of the available music tracks. The selected music pieces should range across musical preferences but be sufficiently rich to enable isolation and dynamic mixing of a sufficient number of different instrumental sections.</p>

These sonifications were aimed at understanding how feedback could be used not just as information but also as a creative process to motivate physical activity. Speakers were placed in the room to produce the sound feedback when using the Kinect system to see what differences arose depending on where (from the speaker of the device attached to the body part exercise vs. the speaker being away from the body) the sound feedback was produced. Next, we describe the wearable device and calibration process.

9.3.2 Calibration process

Given the high variability between physical and psychological capabilities in people with CP, it is important to calibrate the device accurately for sonification. In a forward reach exercise for example, trunk bending may vary between a few degrees to almost 90 degrees (Singh et al., 2014). The calibration of the sonification (SEs) was performed through self-exploration of the movement followed by setting three anchor points associated with particular body positions. In case of the Kinect the person would stand in front of the device and signal verbally when they had reached the desired body position (e.g. maximum stretch) and the researcher would set the particular anchor point through the GUI and confirm to the user. In case of the wearable device, participants would press the calibration button they were holding and the smartphone (worn on the trunk) would capture the orientation of the smartphone device (associated with the degree of trunk bending) as the specific anchor point and confirm the calibration through voice feedback. Anchor points are associated with specific sounds and the space between them is equally divided into intervals that serve as intermediate milestones to drive the sonification. The number of intervals depends on the sonification used, as described in the next section.

9.3.3 Implemented SEs

Using the *Go-with-the-flow* framework and the above devices, we designed a set of SEs to run user studies to validate the framework and to suggest further refinement. The sonic material used to implement the SEs consisted of pre-recorded sampled sounds with instrumental or naturalistic content, music tracks and breathing sounds as described in Table 9-2.

Table 9-2: Description of the implemented SEs for the forward reach exercise. These SEs were also used to sonify the bending forward (till C) of the sit-to-stand first phase.

SEs for Forward Reach and for Sit-to-Stand (Phase 1)					
Sound Name	Sonification of trunk bending	Anchor S: Standing position	Anchor C: Point of comfortable stretch	Anchor M: Today's maximum stretch	SES Boundaries
Flat (Fig. 1 top)	11 repetitions of the same tone from a piano instrument. These were spaced equidistant from each other between S and M.	Sound starts as soon as bending forward starts	None	Sonification stops	<u>Kinect</u> : The sonification occurs only between S-M
Wave (Fig. 1 bottom)	Formed by 2 major scales separated by the anchor point C: 7 equidistant ascending tones before C and 4 equidistant descending tones after C. The piano instrument was selected		Highest tone	Lowest tone of the descending scale Note: In phase 2 of sit-to-stand a tone from the clarinet was	<u>Wearable</u> : the sonification continues on the lowest tone after M The sonification is played in reverse as the

Sound Name	Sonification of trunk bending	Anchor S: Standing position	Anchor C: Point of comfortable stretch	Anchor M: Today's maximum stretch	SES Boundaries
				played	person moves backwards
Water	Continuous sound of moving water with a sound of a splash suggesting the body enters the water		Splash	None	The sound is continuously played until the person returns to S
Windchimes	Continuous sound of windchimes		None	None	
A walk in the forest	Soundscape: stepping on leaves, birdsong, a river, sheep bleating, nightingale. The list of sounds is played sequentially in the order above as the amount of stretching increases.		River sound	Nightingale	Beyond M, sound played at M continues. The sonification is played in reverse as the person moves backwards Note: In phase 2 of <u>sit-to-stand</u> the sound at M is continuously played.
A song	Active Music Listening: interactive orchestration of the song (<i>"I'll be there for you"</i>). Instrument tracks (shakers, percussion, lead vocal, piano, string) are incrementally added as the amount of stretching increases		Lead vocal track	All instrument tracks together	

The first set of SESs was based on a forward reach stretch exercise commonly used in physical rehabilitation of chronic low back pain (CLBP). The forward reach stretch has two phases: reaching forward and returning to a neutral standing position. This exercise induces anxiety due to the stretching movement and the forward shift of the body's centre of mass creating a less stable position. This set of SESs was implemented on both wearable and Kinect-based devices. Next, a set of SESs was implemented on the Kinect for the sit-to-stand movement to explore generalisation of the framework across exercises and investigate sonification to facilitate preparatory movements. Sit-to-stand is complex with two main phases including a preparatory one where the trunk is bent forward to provide momentum to stand up. Stiffness and anxiety are associated with avoiding the preparatory forward bending leading to increased difficulty, instability, and possibly increased pain on standing. The implementation of the sit-to-stand tracking and sonification was done by Genoa based on our framework.

For these two exercises, three anchor points, hereafter referred to as S, M, and C, were designed to define boundaries and milestones within the SESs. S corresponds to the body position before starting the exercise. This is important as people with CLBP may have an asymmetric standing position due to pain. M indicates the maximum amount of movement to be performed that day

(today's target) and C is an intermediate body position between S and M. The anchor points mark specific boundaries within the SES so that people could easily understand the position of their body within the space; anchor points could also be used to signal the reaching of defined milestones to provide a sense of achievement and were calibrated before starting the exercise as described in 9.3 .

The set of SESs created for the forward reach stretch are described in Table 9-2. The C anchor point for the forward reach corresponds to a comfortable amount of stretch (not inducing anxiety). For the sit-to-stand exercise, sonification had two parts: (i) sonification of the preparatory movement (bend forward) using the SESs defined for the forward reach (Table 9-2), and (ii) sonification of the standing up movement on the vertical axis triggering different effects depending on the sound choice (see Figure 3: Anchor M and SES boundaries), ending when the person was fully standing. In terms of anchor points, the C position in sit-to-stand corresponded with a comfortable trunk bending position for the person before standing up. No maximum bend position was set. Even though, in an ideal case, the shoulder should be aligned over the ankles to provide sufficient momentum to stand up, not all people with CP can reach such a bend position due to anxiety or body size. Hence, people were asked to bend to a comfortable extent to facilitate the shift of weight forward for standing up. The M position of the sit-to-stand corresponds to the standing posture at the end of the sit-to-stand movement.

9.4 Chapter summary

In this chapter, the *Go-with-the-flow* sonification framework was proposed for defining sonified exercise spaces (SESs) for physical rehabilitation in CP. The use of sonification is not novel in physical rehabilitation and motor learning (Kleiman-Weiner & Berger, 2006; Hermann & Zehe, 2011; Schaffert, Mattes & Effenberg, 2011), but our approach differs as it is tailored for psychological capabilities, i.e., what the person feels s/he can perform. Rather than aiming for rapid increase in physical performance (Vogt et al., 2009), our SESs are designed to build confidence in movement and to reduce anxiety. Through tailored sonification using anchor points, the SESs provide information about movement to increase awareness of physical capability, normalise body cues, highlight use of protective behaviour, increase motivation and facilitate transfer of skills to everyday activities that are feared or perceived as demanding by people with CP.

In the next chapter, we report on three studies to evaluate the *Go-with-the-flow* framework with people with CP. The next chapter first describes the evaluation of the framework in a controlled situation. Then, Section 10.2 reports the results from a focus group following the control study and a survey conducted with people with CP at the hospital at the end of their usual pain

management session. Finally we discuss the implications of the results and suggest further refinements of the framework.

Chapter 10 Evaluation of the Go-with-the-flow framework

Various studies were carried out to evaluate the effectiveness of the Go-with-the-flow framework in supporting psychological aspects of physical rehabilitation. A set of SESs was created by using the framework (Boxes 2 and 3) of Section 3 and implemented in the two sensing and sonifying platforms described above. We hypothesised that:

1. The use of sonification (vs. silence) is more motivating, increases self-efficacy and body awareness during anxiety-inducing exercises. The richer the information the SES provides about a person's movement, the more effective it is in increasing self-efficacy, awareness and motivation in doing the movement.
2. Simple tone-based sonification paradigms enhance self-efficacy and sense of control given their simple mapping between movement and SES. In contrast, naturalistic soundscape paradigms induce relaxation and promote exploration of movement; active music listening increases motivation given the more complex sonification and creative process involved.
3. SESs calibrated to perform functional movements can facilitate transfer of physical capabilities from exercise to everyday life activity.
4. Sonification alteration techniques enhance awareness of use of avoidance strategies and induce exploration without increasing anxiety.

Next, we present three studies to evaluate the *Go-with-the-flow* framework with people with CP. In the next section, we present a controlled study. In Section 10.2 we report the results from a focus group and a survey at the hospital at the end of a pain management session before discussing our findings.

10.1 Methodology

Participants and setting

15 people (36–68 years; 10 female, 5 male) with CLBP for 6–40 years were recruited from the NHS and using social media and the Emo&Pain project website (www.emo-pain.ac.uk). Participants completed questionnaires about medical information, physical activity and pain catastrophising and rated their pain level at the time on a scale of 0 (no pain) to 10 (worst pain), and comfort level in stretching exercises.

The study was conducted in a lab setting. An adjustable bench was used for variable seating height when doing the sit-to-stand exercises. The Kinect sensor was placed facing the seat and a single video camera was placed next to it to record experiments for later analysis and discussion (see Figure 10-1 for layout of room). The Kinect sensor was 1m from the floor and between 2 and 2.5m from the participant as recommended in the device specification. Participants wore the wearable device (tabard and breathing sensors (Figure 9-2)) throughout the study. Participants stood in front of the seat facing the Kinect to exercise. All behavioural data from the motion sensors and from breathing sensors were captured and stored.

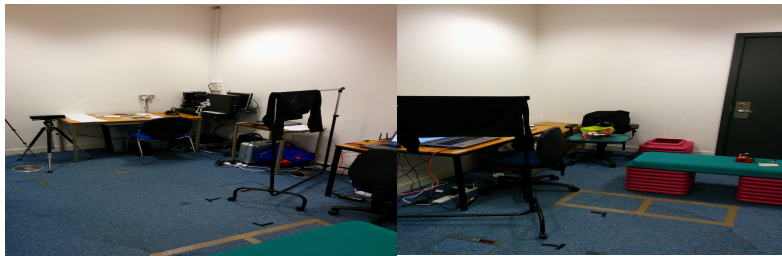


Figure 10-1: Layout of room for evaluation study for both devices.

Procedure

After a familiarisation session with the devices and the sonifications listed in Table 9-2, the study was conducted in four consecutive parts:

- **Part 1:** Effect of sonification paradigms. The Kinect device was used to investigate the effect of three different sonification paradigms (wave sound, soundscapes and active listening on forward reach and sit-to-stand exercises).
- **Part 2a-b:** Effect of information. The wearable device was used to investigate how the different amount of movement information provided by the sonification (i.e., shape and anchor points) facilitated the forward reach exercise. The four sound conditions (no, flat, wave, water sounds) were repeated without (Part 2a) and with (Part 2b) breathing sounds.
- **Part 3:** Effect of information on skills transferring. The wearable device was used to understand how sonification could facilitate the transfer of skills from exercise to a functional activity. Participants were asked to reach forward to get something from a shelf at a challenging height (with a target: the shelf) or to simulate taking something from the same height (without a target in front). M was recalibrated according to the stretch needed to reach the shelf. The four sound conditions (no sound, flat sound, wave sound, water sound) without breathing sounds were explored.
- **Part 4:** Effect of sonification alterations on movement avoidance. This was run as a qualitative study. At the end of Parts 1-3, the sonification alteration option was activated on each of the devices and participants were invited to explore the various techniques

implemented (Box 3) and comment on their usefulness in increasing awareness of avoidance strategies.

For each part of the study, participants calibrated the anchor points (S, C, M) for each device (Kinect or smartphone) according to their physical and psychological capabilities. For the sit to stand, the height of the bench allowed an approximate 90° angle at the knee, with feet just behind knees, to encourage the preparatory bend forward position preceding standing. In each study, the presentations of the sound conditions were randomised.

During the familiarisation session, participants explored their movement with each sound condition, giving researchers a commentary on their movement and any pain or anxiety ratings. This enabled participants to become familiar with the devices and exercises and researchers to informally sample effects. In each part of the study, immediately after each sound condition, participants were asked to rate their pain on a scale from 0=no pain to 10= worst pain, and their perceived bend angle on a 5-point scale (five bins centred at: 15°, 30°, 45°, 60°, 75°). Such a fine-grained scale was selected as we expected small variation effects due to anxiety. After completing the four parts of the study, participants indicated their preferred sounds and how each sound affected their awareness of movement, motivation, performance (measure of confidence), and relaxation on a scale of 0=worst to 6=best. It should be said that the ratings related to motivation indicated how the person felt during the execution of the exercise (desire to perform the movement). Long-term studies will be needed to assess the long-term motivational effects of the sonification conditions. Table 10-1 summarises the four parts of the study with descriptions of the corresponding independent and dependent variables.

Each participant took between 60-90 minutes to complete the full study over two weeks of data collection. The analysis of the participants' movement is discussed in the next section. The participants' comments were used to inform the design of the focus group (Section 10.2) and will be reported with those findings.

Table 10-1: Description of independent and dependent variables for each part of the study. Within each part the sound conditions were randomised.

Experiment	Device	Exercise	Independent variables	Dependent Variables
Familiarisation	Both devices	Both exercises	n.a. (all sounds)	n.a (Think Aloud)
Part 1: Effect of sonification paradigms	Kinect-based device	Both exercises	3 SESs: wave sound, naturalistic soundscapes, active listening	Actual amount of movement measured by the device Perceived amount of movement Awareness of movement Motivation in moving Confidence in moving Relaxation
Part 2: effect of sonification information: (2.a) without breathing; (2.b) with breathing	Wearable device	Forward reach	4 SES: no sound, flat sound, wave sound, water sound	
Part 3: Effect of sonification in transferring skills	Wearable device (without breathing)	Forward reach with and without target	4 SES: no sound, flat sound, wave sound, water sound	
Part 4: Efficacy of sonification alterations on awareness of avoidance strategies and movement exploration	Both devices with alteration option on		n.a.: explorative study; all alteration techniques presented in Box 3	n.a: explorative study (Think Aloud)

10.1.2 Results

In this section, we report the statistical comparison of sonification effects during physical activity using questionnaires and behavioural data from the movement sensors. The independent variables (Table 10-1) were the sound conditions: three in Part 1 with the Kinect device; four sound conditions in Part 2 using the wearable device; four sound conditions with the addition of breathing feedback in Part 3. For each measure, non-parametric Friedman's tests between the sound conditions and planned pair-wise comparisons using Wilcoxon were performed for the non-normal data, while parametric analysis of variance (ANOVA) with sound conditions as within-subject factor and planned pairwise t-tests comparisons were performed for the normal data (normality was checked with Shapiro-Wilks tests). Notably, sound feedback did not show a significant effect in pain reports across conditions in either device (Friedman's analysis of variance, all $p > 0.1$). Detailed statistics are reported in Appendix F.

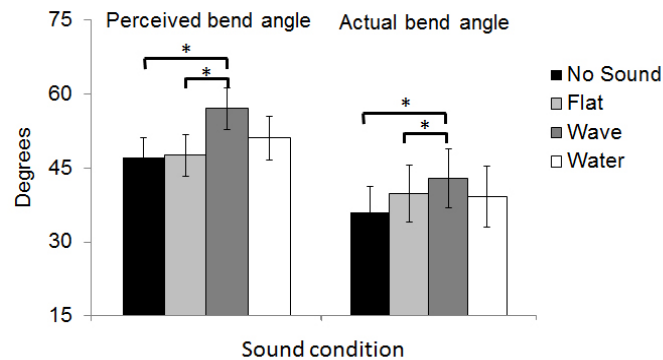


Figure 10-2: Mean (\pm SE) perceived and actual bend angle for all four sound conditions in the study with the wearable device. The perceived angles were obtained by translating the 1 to 5 ratings to the respective range of angles centred at 15°, 30°, 45°, 60°, 75°. * indicates significant differences ($p < .05$).

Parts 1-2a. Effect of different sonifications on perceived and actual performance

First, we evaluated the effect of the sound feedback conditions for perceived and actual performance (bend angle) in both Part 1 and Part 2a. Whereas no effect of complexity of sonification paradigms (Part 1) on performance was found, an effect was found for the amount of movement information provided by the sonification (Part 2a). The wearable device (Part 2a) provided different levels of information (anchor points and sonic phrase shape) in the sound. The mean values for perceived bend angle, as reported by participants, and for the actual bend angle, as recorded by the sensing device (where 0° corresponds to the vertical position of participants, and 90° corresponds to their back being bent forward until reaching a horizontal position), are displayed in Figure 10-2. Results revealed a significant effect of the sound feedback condition in both the perceived and the actual performance: participants felt they were stretching more with the more informative wave sound than with the flat sound or no sound conditions, similar results were found for the actual amount of bend.

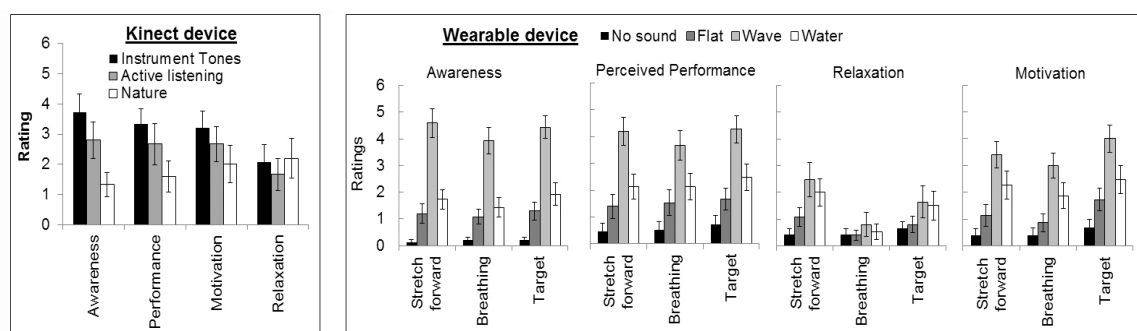


Figure 10-3: Mean (\pm SE) ratings (0=worst to 6=best) on awareness, performance, motivation and relaxation for all four sound conditions in the study with the Kinect (left) and the wearable device (right). For sake of conciseness, the significant differences are reported in the text and in Tables F.2-F.5 in Appendix F.

Next, we examined participants' reports of how they felt each sound condition influenced their performance, awareness of movement, motivation and relaxation. Participants mean ratings, on 0 to 6 scales, are displayed in Figure 10-3

Part 1. Effect of sonification paradigms on exercising (F.2 in Appendix F).

Significant differences were found between the different sonification techniques used in the Kinect device (Figure 10-3 – left). Participants reported changes in awareness of their movement according to sound condition, with less awareness of movement in the soundscape (walk in the forest) condition compared with wave sound (tone phrases) and active music listening. In addition, the results suggested that perceived performance was better with the wave sound than in soundscape, although the overall effect of sound on perceived performance did not reach significance ($p = 0.097$).

Part 2a. Effect of information (anchor points) on exercising (F.3 in Appendix F).

In the study with the wearable device when participants stretched forward without a target and without respiration feedback, they reported significant differences in all measures. As shown in Figure 10-3 (right) most participants found sound significantly more useful on all the rating scales than no sound. Results also suggest that more informative sounds are more effective, hence significantly higher ratings with the wave sound (with 3 anchor points and ascending and descending scales) for awareness and performance. For relaxation and motivation, wave and water sounds were significantly better than flat sound but not significantly different from each other.

Part 2.b Breathing reminders are liked but confusing.

When an additional sound to remind people to breathe was added, a minority of participants (6 out of 15) said it made them more aware of their movement and could help performance, but most found it neither relaxing (14 out of 15 participants) nor motivating (13 out of 15 participants) (see Figure 10-3 - right). Participants commented that while a reminder for breathing was helpful, the two sounds (for movement and breathing) were confusing, and the breathing sound was disliked. No significant difference was found between no sound and having only respiration sound for any of the ratings (all $p > 0.5$).

Part 3. Sonification to facilitate transfer from exercise to function (F.4-5 in Appendix F):

We compared the effect of sonification when performing the functional activity of taking an object from a shelf at a challenging height and when simulating the same activity (i.e., without the shelf as a target). Awareness of movement, perceived performance, relaxation and motivation mean ratings were compared in two-tailed Wilcoxon paired comparisons ($\alpha=0.05$). The results are shown in Figure 10-3 (right). Participants reported that they felt more motivated and thought they performed better (12 of 15 participants), and were more aware of their movement (13 of 15 participants) with the shelf present. In the “no sound” conditions, there was

no difference in ratings of performance, confidence, or motivation with or without a target (all $p > 0.1$). However, with the wave sound participants felt they performed significantly better with a target compared to without the target ($p < 0.05$) even if they were less aware of their movement. There were no effects for the other sounds. Motivation was rated significantly better for all sound conditions with a target, but having a target did not significantly affect relaxation ratings for any of the sounds. When comparing the effect of different sonifications on the execution of the movement with target, participants reported a significant increase in awareness, better performance, and greater motivation with more informative sounds. These two results together suggest that both the type of sonification and the type of activity (target-oriented vs. not target-oriented) have an impact on measures.

In the next section, a follow-up focus group and a systematic analysis of people's comments from this controlled study are reported, to get a better understanding of how the sonification space and strategies proposed address the needs of self-directed rehabilitation and function, and how they could be extended to be more effective. In addition, to confirm the results from the controlled study, we include the results from a survey conducted at a weekly drop-in group run by physiotherapists at the pain management centre for people with CP.

10.2 Factors in designing SES for Exercise and everyday Functioning

A focus group and a survey were run to understand how a device such as *Go-with-the-flow* (both versions) could be used for exercise sessions and functional activity in everyday life. Research questions addressed by the study were:

1. *Can people design exercise spaces using sound? Can anchor points or other sound-based information increase self-efficacy?*
2. *To what extent is sound sufficient to represent information about physical activity?*
3. *Can sound be used for setting targets for activity and identifying similarities between exercise demands?*
4. *Can sound be designed to facilitate transfer from exercise to functional activity?*

10.2.1 Methodology

Focus group

The structure of the focus group was based on findings from discussion with participants during the study reported in section 4. Five people (4 female and 1 male) from 44 to 58 years, with CP for the past 7-39 years, participated in the two-hour focus group. Participants had already participated in the study reported in the previous section and were familiar with the sound conditions. A pre-focus group activity was set a week before the study where participants were

asked to reflect on and email the researchers about whether the sounds used in the previous study could support them in household or everyday functional activities and exercises that they were anxious about. They were also asked to think about sounds that they find motivating or relaxing while doing activity.

The focus group included a discussion and also trials of the sonification options by participants to facilitate discussion. The Kinect was setup at one end of the room for people to try. Sound cards were provided with the sonification options from the study, such as nature sounds, songs, tones and instrument sounds to facilitate exploration and discussion. A keyboard was available for the tone scales from various instruments. Further sound cards were created for sounds mentioned by participants during the evaluation study, such as white noise. We also provided smartphones with the *Go-with-the-flow* app for people to explore during different stretching exercises. The focus group discussion was recorded with two video cameras at opposite ends of the room and two audio recorders.

Survey at a drop-in session at the pain management centre

To further understand how useful the different sonification strategies were to people with CP, we collected data at a weekly drop-in group run by physiotherapists at the pain management centre of the National Hospital for Neurology and Neurosurgery for people of different abilities to attend for stretching and exercises. The Kinect and wearable devices were set up in a corner of the room beforehand the pain management class and interested people were given a demonstration of the movements and corresponding sonification options and encouraged to try both devices and to answer questions. This study was not audio- or video-recorded and ran for 30 minutes on two days. 10 people participated (6 female) aged from 32 to 68 with CP for between 4-61 years. They were asked to evaluate all the sonifications, organised in three separate classes: nature sounds (all nature sounds from the Kinect and the smartphone device), tones-based sounds (flat and wave) and active listening sonification.

10.2.2 Findings

The survey findings (see Figure 10-4) confirmed the results from the control study: all participants reported that the sounds were useful; sonification was described as encouraging (5 people), fun (5 people), relaxing (5 people), informative (5 people), and distracting from pain (1 person). Nature sounds (from the Kinect or wearable devices, counted as one for the same person) were most popular, followed by the tones-based sounds (flat and wave) and by the active listening sonification. Nature sounds were also the more relaxing, followed by the tones-based and the active listening sounds. The active listening sound was considered most

motivating, followed by the wave tones. However, the tones-based sounds were reported to be most helpful for performance and awareness of movement.

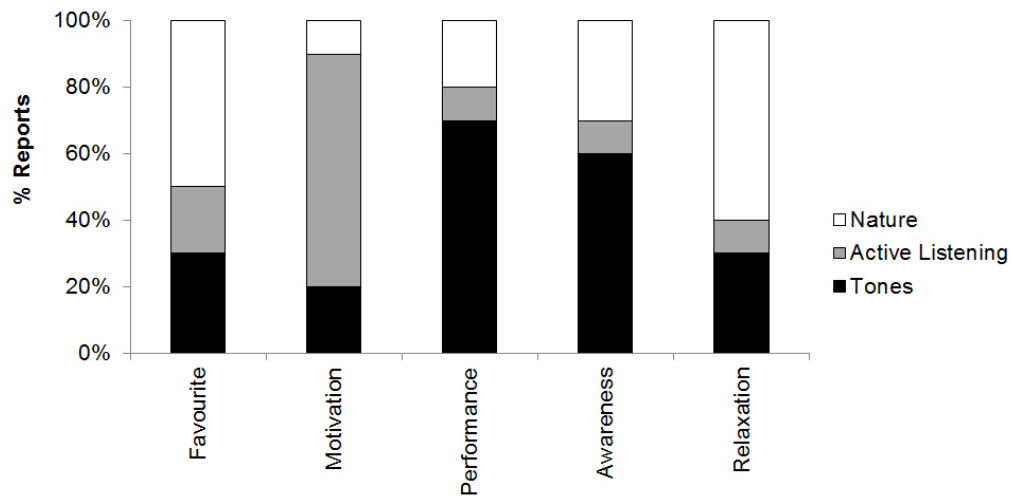


Figure 10-4: Distribution of results for all the sounds. Nature-bin refers to both Kinect nature sound and water sound from the Smartphone device. Tones-bin refers to both Smartphone and Kinect tone sound. The flat sound was never selected.

The qualitative studies helped to further understand these results and shed more light on the value of the sonification framework. Transcripts and observations from the focus group, interviews, and exploratory sessions described in the previous section were analysed together using thematic analysis (Braun & Clarke, 2006). The six main themes that emerged are discussed using the following notation: FG# denotes focus group participants and ES# denotes participants from the evaluation part of the controlled study.

Enhancing awareness through sound feedback

Most people liked sounds that focused attention on their movement, allowing them to understand and adapt or change the movement accordingly. For example, the wave sound was most popular because most participants felt that it accurately described the forward reach movement and they could see the relation between the change in sound and the movement they were doing. FG3 said, *“That piano is fine on the way down as well, because I can tell when I’m getting to the comfortable point and I can tell when I’ve got to the extreme point because it stops and I like that.”* Participants indicated that it would be useful to have a distinctive sound signal to indicate reaching the target or returning to the start position (e.g. higher volume (FG2) or the clash of cymbals (FG3)).

While participants liked the nature sounds, they found them distracting and could not always understand or directly relate their movement to the information being conveyed by different sounds. More complex sounds such as the naturalistic soundscape made some people more anxious about stretching. FG1 said, *“Sounds must not be disruptive and take away from what*

we're doing, which is the stretch. And if they are disruptive then it doesn't allow us to concentrate on the stretch and there's a danger that we're going to stretch too far - we're going to hurt ourselves." One of the problems with the complex sounds was that it was difficult to understand where one sound ended and the next started. The speed of performing the movement was a factor: if the movement was executed rapidly, separate sounds were merged or skipped.

Participants also felt that the sound should reflect the type of activity. FG2 said, *"So if you're going to do cardiovascular exercise, you don't want gentle music. You want something quite brisk."* One suggestion shared by most of the focus group was using sounds that were both relaxing and informative and reflected the *'body's rhythm such as beats that are not very loud and set to the pace of the heartbeat'* (FG5). FG2 said, *"In the same way that the brain and the music won't have a very fast rhythm, you won't have a very intrusive rhythm, track or some techno or something like that."* Some participants commented that having a voice telling them to stretch, or reminding them to breathe, could be very reassuring and encouraging. FG4 said, *"Some kind voice that's telling you to stretch, because it's something that connects with another human being."*

Information about movement restriction and avoidance strategies

Participants knew that at times, and especially when tired, they used protective or avoidance behaviours such as guarding and restricted movement patterns, posture change (e.g. slouching or leaning to one side); sometimes they were made aware of this by catching their reflection in the mirror or being told by someone else. They liked the idea that they could use the Go-with-the-flow device to get information about these behaviours alongside information about breathing, asymmetric movement and pace of stretch.

While protective behaviours are intended to minimise pain, they often exacerbate it in the medium to long term. FG5 mentioned, *"I don't always realise that's [using protective behaviour] happening enough and it takes somebody to point it out to me, but if I had some feedback to say I'm leaning forward or I'm leaning to the side or I'm starting to limp, that [awareness] might kick in a little bit sooner."* The Go-with-the-flow app can provide cues about different movement patterns but does not correct; participants felt that it could help them to make a choice to stretch or take a break or simply adjust their movement. FG5 explained, *"Posture for me is something that feels like a weight on my back and it just feels as though I'm carrying this rucksack that I can't take off. I end up, without realising, becoming very hunched, and then I end up hobbling around the kitchen and that's when my husband will tell me, 'Just go and have a sit down.'"*

Whereas our design provided alterations on the basic sounds, from those that were still aesthetically pleasing to slight distortion, some participants suggested more aversive sound feedback (ES7) could emphasise undesired protective movement or movement restriction. Others suggested that to facilitate conscious avoidance of protective behaviour, white noise rather than a more complex sound would help them to focus on the quality of movement by blocking out distractions.

Facilitating control and increasing confidence

Defining and calibrating a movement space: People liked the ability to define their movement space using the three anchor points of starting position, comfortable position and today's target position. In addition, they felt that they might not always need the maximum point for a target, especially if they were having a bad pain day when they would only try to get to the comfortable point. Participants felt the device could provide additional helpful information for self-directing activity. For example, FG2 mentioned "*an element of timing so I was stretching far enough and holding it for long enough*".

Having a rich but clear information soundscape: While the information conveyed by sound was useful, participants felt that it was important to ensure that the purpose of each dimension of sound was clear. FG5 said, "*On the trial that I did, you had music becoming loud and soft as I moved fast, that was useful.*" FG2 added "*one advantage of [sound] is you've got three dimensions: you've got frequency, amplitude and time [...] and distortion – that's a lot of information that can be used.*" Some sounds also encouraged people to try new movements, not suggested by the researchers. For example, when using the water sound some people started spontaneously making swimming movements. Hence, the design of the sound could go beyond just pleasurable stimuli and clear information, to designing sound that relates to and may prompt particular movements.

Trusting the body (overcoming caution): Sound feedback allowed participants to appreciate their range of movement, build confidence and to set benchmarks, so that they knew that if they could do a certain amount of movement on an average pain day, they could try at least to get to that comfortable point on a day with more pain. FG3 said, "*At the moment I wouldn't go beyond what I think is my comfort point because I'm worried about making it worse. If I know I haven't reached it because the thing hasn't told me I've reached it, I might try and push through to that comfortable point. [...] having got there, I won't go any further, but I think it would encourage me to trust my body to the point I could get to yesterday at the very least.*" Setting the comfortable point was also considered reassuring and most people felt it could help them to overcome the fear of moving and build confidence in movement. For example, FG2 said, "*my*

proprioception is poor with my back because of fear. And even though the fear is very real, it's not even a conscious fear; it's something that's definitely ever-present. And something like this would tell me, tell my intellect to overcome my fear, because you've got this far, you can go again."

Monitoring the body, pain triggers and progress

Participants felt that a *Go-with-the-flow* device could be useful for tracking stretches over a longer period of time to track improvement or continued maintenance of stretching ability. FG1 said, *"If I could look at it for a whole month and realise 'I've got through a whole month, I've reached my maximum point'."* FG2 added, *"For some people it's just about maintaining something, but for other people it's if you have a degenerative disease, you can see the progression of degenerative disease by loss of ability, so if you can see some element of, 'I'm still maintaining the posture where it should be for fifteen years', that is a good thing."* All the participants agreed that viewing progress was motivating. *"I've had a couple of low days but generally my comfort point has stayed the same or got slightly further, I think that would be very motivating to see that."* (FG5).

For many participants, it was important that the device should monitor their movement, breathing, and muscle activity over a period of time and track flare-up triggers; this would enable the device to help them set limits and pace their activity better. FG3 explained, *"Something like this would be quite useful if it was monitoring that if I'm leaning to one side and it pings at me, I'll know that really today I should use the escalator, it's telling me that I'm already off-centre. [...] it would help me to make a choice, a decision about, 'Do I stop now, cause I can now, and do some stretching, right now, using this to help me pull this muscle back out again?'"* Further the device could be useful to plan for anticipated stressful events. ES1 said, *"I know that we're going on holiday. We've got ten hours on an airplane: I need to make sure I don't overdo it."*

Facilitating transfer and facilitating functioning

The *Go-with-the-flow* device, particularly the wearable device, was considered a useful aid to facilitate transfer of skills from physiotherapists and a tool to help maintain activity levels. Focus group participants felt that the device could be very useful to practise after they had worked with a physiotherapist/ instructor on calibrating their stretch current capability and set targets. FG2 suggested, *"Particularly [useful] if I can work with my physio and my Pilates coach, we can work together to calibrate something like this"*.

The focus group study also highlighted that it was important for people with CP to interweave activity and exercise or stretching to maximise time for routine chores, to use their time better or even to avoid increased pain because they felt stiff after doing one thing for a prolonged time. Most participants felt that the device could make them aware of any awkward movements or use of protective behaviour while doing functional activity, thus helping to address unhelpful automatic behaviours that had developed over a period of time. The mobility of the smartphone device was considered advantageous by all participants as it meant that the device could be used in many naturalistic situations. For example, HCP3 said, *“I would love to use some gentle music, something to motivate me, take my mind off the pain and grogginess and help me get started. Possibly music to go with stretches I can do in bed.”*

Most participants described their tendency to be either too active or too inactive, a typical cycle seen in CP where overdoing activity can be followed by rest days to recover.

Type and location of feedback and context of use

Most participants preferred the sounds coming from the smartphone rather than the speakers in the Kinect scenario as they felt that the smartphone provided more precise information, in particular the wave sound: they felt *“more connected”* (FG4) and *“the pleasurable sound came from a painful part of the body”* (ES1). However, the breathing sounds coming from the smartphone placed on the back of the person was anxiety-provoking for some people because they felt it resembled someone breathing heavily just behind them, a threatening cue. This indicated that for some sounds, the location of origin of sound is very important.

Some participants found that the pleasurable sounds distracted them from pain. Certain sounds, such as water, were perceived as relaxing and people felt that they could use them to stretch on stressful days. Some participants were keen to wear the device as they performed activities in their daily lives. They visualised the device as a phone on their back or a vest with sensors and sound feedback. However, they felt that haptic feedback would work better than sound feedback when they were in public places, *“One of the things that would put me off using this in everyday life would be walking down the street having a voice in my back going bing bing bing bing”*(FG1).

10.3 Discussion

In this chapter, we presented studies conducted to validate the *Go-with-the-flow* framework with people with CP and physiotherapists using two iteratively-built devices: a smartphone-based wearable device and a Kinect home-based system. The evaluation was done using control studies and qualitative studies in the lab and at the hospital. The results of the control study

reveal that people found that sound feedback for all sonification conditions was always preferable to no sound feedback on all rating scales (awareness, performance, motivation and relaxation). More informative SESs scored significantly higher on all the scales except relaxation. Also, people showed a preference for less complex but more informative sonifications. Sonification alterations were well received by both people with CP and physiotherapists for their potential in improving efficacy of physical activity sessions. In addition, the wearable device demonstrated the possibility of skills transfer from exercise to functional movements through calibration of the device to everyday activities. Qualitative studies confirmed these findings and further highlighted how the device could be calibrated and where and how it could be best used by people with CP.

In the remainder of this section, we present four main points that emerged from this work and discuss implications of the sonification framework and findings from evaluation studies on the design of technology for physical rehabilitation in CP. We use (Pr#) to refer to the principles in Box 1.

10.3.1 Informative personalised SESs increase self-efficacy

Specific sounds are commonly used for signaling goal achievement or providing feedback on the quality of movement (e.g., Wallis et al., 2007). However, we used *anchor points* (Pr4) within SESs to tailor the sonification strategy to the psychological needs of the person. Of the three anchor points, we found C (the comfortable anchor point) was the most critical in facilitating exercise in CP. In contrast to other rehabilitation studies, recalibrating C to the physical and psychological needs of the day rather than according to a schedule of continuous progress (Lewis & Rosie, 2012) was an important aspect of self-management (Pr7) to avoid strain in CP. Both people with CP and physiotherapists agreed that M (i.e., maximum stretch) was not always needed and that encouraging a minimum amount of movement was more important. Reaching C (i.e., comfortable point) provided a sense of achievement both on bad pain days and good days (especially if the mood was low as discussed in previous chapter) by marking what the person “*needs to do*” and motivating them to go a little further, “*any extra is a plus*”. Hence, C rather than M may be seen as the goal that facilitates not only maintenance but also steady incremental building over time of physical and psychological capacity.

As expected, our results showed that the combination of C and M (“today’s target”) could facilitate maintenance of gains on good days. In the wave sound condition, people reported that the achievement of reaching C was a motivation to continue to the final target. However, simply marking the attainment of a final target or goal was not in itself effective, even with sounds played at incremental steps (flat sound condition). Even though some participants still pushed

themselves to reach the target, endurance without awareness risks strain, in turn producing setbacks and generating protective behaviour. Even when relaxing naturalistic sounds (Vogt, Pirrò, Kobenz, Höldrich, & Eckel, 2009) are used, simple feedback of progression towards a challenging target may not be sufficient to reduce anxiety (e.g., nature sounds in the Kinect device, and the active listening condition, where meaning was unclear).

Sonifying preparatory and protective movements for more effective movement

The use of sonification to discourage compensatory movements is not novel; many rehabilitation systems have used sound and sound alterations to signal compensatory movements, such as in stroke rehabilitation (Rosati et al., 2013; Roby-Brami et al., 2014) or balance in elderly people (Paraskevopoulos et al., 2014). However, protective movements and avoidance of facilitating movement in CP are usually attributable (until completely habitual) to anxiety about increased pain or injury, so sonification needs to be tailored to these psychological concerns. Further, our studies showed that facilitating movement was more encouraging and useful rather than correcting. Hence, increasing awareness (Pr5) and allowing exploration of helpful preparatory movements (Pr6) may be more effective than simply correcting movements; especially since most people with CP wanted to be made aware of their protective behaviours, but they wanted to be in control of their response to the information (e.g., do some counter-stretches, or rest). Hence, it is important to design sonification options in ways that reinforce a sense of control and encourage self-management (Pr7).

We also explored breathing as part of relaxation and to address anxiety during physical activity: using breathing sensors for signalling shallow or mainly thoracic breathing (rather than diaphragmatic) or holding breath, which can potentially affect ease of movement due to anxiety (Perri & Halford, 2004). Breathing well may also make certain movements easier. We used sound feedback to remind people to breathe deeply but while this increased awareness of breathing, its design was not effective since the pre-recorded breathing sounds were not perceived as self but as another person (too close behind), and distracted from sonified movement probably through auditory overload (Lavie, 2005). The fact that the breathing sound was not accurately synchronised with their own breathing was possibly an important contributing factor. Our experience with breathing demonstrated that the position of feedback may also be an important design consideration: sounds from behind the listener are more arousing and elicit larger physiological changes than sources in front (Tajadura-Jiménez, Larsson, Våljamäe, Västfjäll, & Kleiner, 2010). One possibility is to integrate breathing rhythms in the movement sonification, starting at the user's rhythm and then slowing and deepening (Liu, Huang, & Wang, 2011). People also suggested using different feedback

modalities such as a person's voice that reminded people to breathe during movement or counting to slow breathing (as the physiotherapist does).

Different sonification strategies for different phases of rehabilitation

In the previous chapter, physical rehabilitation is described as a journey with different phases (exploring, building and maintaining). Our studies show that different sonification strategies could facilitate different needs in these separate phases. For example, simple sonifications, such as the wave condition for the forward reach in the mobile device, were more effective in enhancing awareness and performance than complex sounds. Such simple sonifications are examples of direct mapping (Hunt & Wanderley, 2002) of sonic parameters (e.g., pitch) on to movement parameters (e.g., stretch extent). Direct mapping is usually easier to understand, but examples of more complex but still effective mappings (usually designed for music professionals) are found in the literature (e.g., Hunt, Wanderley, & Kirk, 2000). In our studies, complex sonifications appeared to be demanding as a source of information on the execution of an exercise, but to have interesting benefits in other aspects of physical rehabilitation, such as relaxation, or practising movements where people had developed confidence (maintenance phase).

Participant feedback indicated that music or sound that is not perceived as directly related to the performed movement should be avoided (e.g., a sudden single singing bird). The sonic material should not contain any explicit sonic event (e.g., a thump, a thunder, a tap), except where its relation to the user's movement or respiration is obvious (e.g., the water splash indicating that a comfortable point was reached). Sonic materials from sound synthesis techniques such as physical modelling (e.g., Rabenstein & Trautmann, 2001) can ensure that parameters are assigned clear physical meaning: for example, the thickness, length, or tension of a membrane or a string; the number and amount of vibration of molecules of water in a waterfall. Thus, a fine-grained, ecological modulation of the naturalistic sonic material is obtained, and may be better suited to the task of reflecting a person's body movement. Moreover, the nature soundscape might "set the scene" before exercise, reducing tension and increasing flow (Gromala et al. 2015). In related work (Timmers, Marolt, Camurri, & Volpe, 2006), to reduce the emotional impact of a piece of music on an audience, a successful strategy was for the pianist to play immediately after arrival, with his ears still saturated by traffic noise. Vidyarthi and Riecke (2013) used breathing sounds to prepare for mindfulness meditation. Similarly, a relaxing, interactive soundscape related to the person's respiration and movement might help him/her to warm up for exercise. Further, in the framework of physical modeling, the application of advanced methods of sonification such as "model-based sonification"

(Hermann, 2011) would be worth investigating. Whereas physical modeling techniques for sound synthesis already have proven effectiveness in music performance (e.g., Castagné & Cadoz, 2014), they have only recently been used for sport and rehabilitation (e.g., Turchet, Pugliese, & Takala, 2013; Roby-Brami et al., 2014).

Body awareness, self-calibration and wearable device can facilitate transfer of skills from exercise to function

An important aspect of physical rehabilitation, though often overlooked in technology design (Bruckner, Theimer, & Blume, 2014; Schmitz, Kroeger, & Effenberg, 2014), is transfer of gains from exercise to real-life function. In our qualitative studies, people with CP reported that they lost their motivation for physical exercise when they could not see any improvement in their daily functioning or progress towards valued goals. The work reported in this chapter could help bridge the gap between guidance and feedback from a live physiotherapist, available only to a small minority of people and time-limited, and help with maintaining and building on treatment gains at home and in the person's own environment. Three elements emerged as critical for transfer to function: (i) body awareness, (ii) self-directed calibration, and (iii) device mobility.

Whilst the field of technology for physical rehabilitation is moving towards user-controlled methods, the physiotherapist is still at the centre. For example, Lewis and Rosie (2012) suggest that the physiotherapist's assistance is important during the initial period of technology use to ensure understanding and appropriate setting of parameters; our findings echo this conclusion. Additionally, our study suggested a more critical role for the physiotherapist (e.g., supporting patients' acquisition of self-calibration skills as a part of their awareness of body movement, rather than performing the calibration for them). Our study indicated that physiotherapists can help patients to reflect on their body representations through sound, and to direct their attention to cues that can help in self-directed activity. By using sonification to enhance body awareness (including protective behaviour), the device could be used by the person with CP to become aware of his/her own body capabilities and limits (e.g., "*at which point of a stretching do I start to use protective behaviour*"), and to test calibration settings. At the same time, our results showed that external representation by sound can enhance patients' understanding of their own movements and breathing patterns (if embodied), and help with providing personalised explanations and advice, facilitating pacing and goal-setting. The supervisory support by the device could be further enhanced by using functionalities to automatically detect increased pain or more subtle cues of fear of pain from body cues (Olugbade et al., 2014, 2015; Aung et al., 2015; Walter et al. 2014) and from facial expressions (Hammal et al., 2012; Kalwang et al.; 2012; Romera-Paredes et al., 2013; Meng et al., 2014) and suggest or guide re-calibration.

Indeed, in a recent follow up study we carried out on sensing wearable devices, people with CP confirmed the role of technology as a support to learning supervision skills and even to share such the supervisory role in real-life situation where the task at hand requires much attention (Felipe et al., 2015).

The flexibility, mobility, and adaptability of the wearable device make it suitable for use across a range of everyday activities, shown here to be relevant to people with CP. In the control study, participants found using the target more motivating but in certain cases anxiety-inducing. The use of a target-calibrated device to practise the movement could facilitate the transition between exercise practice and targeted activity (functional goal).

Overall the results of the evaluation of the framework and of the device were quite positive however, exercise is only a small part of the physical activity a person with CP has to engage with. Hence, our next step was to understand how such a framework and sensing and feedback technology could facilitate self-directed everyday activity in the home. This is the focus of the next part of this thesis.

Part III

“Functioning”

Chapter 11: Everyday functional activity in the home using *Go-with-the-flow*

Chapter 12: A new Framework for designing Technology for physical Rehabilitation technology (RaFT)

Chapter 11 Everyday functional activity in the home using *Go-with-the-flow*

In the previous chapter, we investigated how the *Go-with-the-flow* framework and device could support people with CP in doing physical exercise. Our findings showed that a self-defined sonified space calibrated to the psychological needs of the person helped to increase awareness, motivation, performance and relaxation in physical activity and could be used by people with CP to gain confidence in activity and had the potential to transfer gains to their everyday lives. The results also suggested that the device could not only support exercise but also functional activity in general. In this chapter, we explore how tracking and feedback technology can facilitate functional activity in the home. Our aim in this chapter is to investigate the third research question of this thesis, shown in Table 11-1 (left).

Table 11-1. Research question and studies for Part 2: “Functioning”. The first study was a home study with contextual interviews, followed by a redesign of the device to enable self-directed use in the home. This was followed by a 7-14 day study of the device in the home. S1 is used to refer to physiotherapists while S2 refers to people with CP in the figure.

FUNCTIONING			
RQ3. How can interactive real-time feedback facilitate (i) self-directed physical activity in the home and (ii) enable transfer of skills from exercise to physical activity?	Study 3A Evaluation through contextual interviews + diary study at home with S2	Redesign Redesign of prototype based on RQ3 findings and Study 3A for self-directed use at home along with additional wearable options and remote control	Study 3B: <i>In-the-wild</i> use of the device in the home over 7-14 day study which included interviews, observations and diary studies.
<i>In Chapter 11</i>			
Outcome: Technology Framework for self-directed physical RehAbilitation (RaFT)			

To address this question, we conducted two studies:

- Exploratory contextual interviews in the home where participants were given the opportunity to use the device. This was followed by a week-long diary study where participants reflected on how the device could be useful to them (referred to as short home study).
- A long-term study (7-14 days) in the home where the device was left with people with CP to investigate how people appropriate the device and feedback for supporting them in self-directed exercise and everyday functional activity. We collected data using interviews at various points of the research, diaries, and sensor data (referred to as long home study).

In this chapter, we first present the rationale for conducting the studies in the home. Existing rehabilitation technology designed for supporting functional activity in the home has been reviewed in Chapter 4. We then present the research questions, method and approach of the two home studies. Finally, we present the results of the studies and discuss the opportunities that technology offers in this context (i.e., beyond exercising). Finally, in the following chapter, building on these findings and the ones from the previous studies, we propose a new framework to guide the design of technology for physical rehabilitation.

11.1 Why home studies?

Conducting studies in the home is important, as within the home environment individuals rather than clinicians control their own energy, time and space (Grönvall & Verdezoto 2013). Technology designers do not fully appreciate the barriers to activity and the use of resources in the home environment of patients (Axelrod et al. 2009). Further, people have little motivation to do activity recommended by clinicians in the presence of physical and psychological barriers imposed by CP and due to the demands of everyday life. Therefore, new technologies for physical rehabilitation introduced to the home may not affect pain management strategies and existing practices (Grönvall & Verdezoto 2013). Considering how diverse people's home environments and everyday needs are, there is also a need to see how people appropriate such technology and how it can facilitate improved quality of life (Axelrod et al. 2009). Since rehabilitation in CP is not just about exercise but also about transferring confidence and skills to functional activity and supporting functional activity, so effective technology needs to be designed to support this. Indeed, as our results showed in the previous two parts, people with CP report that they have limited capacity for exercise, given the lack of physical resources and their everyday functions.

The home space poses many technical and design challenges to the use of rehabilitative technology and there are very few examples for technology that supports people in doing functional activity in the home space as we discussed in Chapter 4. We highlighted in Chapter 4 that while rehabilitation technologies designed for the home took motivations of individuals into consideration during rehabilitation, they were not designed to facilitate everyday functional activities (e.g., Bagalkot et al. 2012; Balaam et al. 2011) and mainly facilitated exercise. Further, some technologies that are designed to support functional activity (e.g., Duggan et al. 2015) and provide support in the form of motivation, setting goals and pacing activities during a functional activity, but they targeted only walking and did not address feared movement.

Our aim in this chapter is to identify the needs raised by everyday functioning and understand the opportunities that the *Go-with-the-flow* framework and run-time movement feedback

technology, in general, offer to people with CP to address their needs. In particular, we were interested in:

- *What functional barriers, routines and needs do people with CP have in the home?*
- *How do people use/appropriate the Go-with-the-flow device to address their needs or overcome these barriers?*
- *How does the use and role of Go-with-the-flow change over time?*
- *To what extent is sound an acceptable modality to support functioning in the everyday functional and social context?*

Next, we present the research questions and the methods used in both studies.

11.2 Study methods

Both studies used multiple methods: contextual interviews, a diary study and observations. In this section we first describe these methods and how they were used in these studies. Then we discuss the specific setup of the two studies separately. Next, we discuss the combined results from the two studies in the Results section. The discussion section focuses on the implications of the results on the design of the *Go-with-the-flow* device and framework.

11.2.1 Study 1: Short home interview and diary study

Participants

Eight participants were recruited for the short home study (see Table 11-2). All participants were women aged between 37 and 58 years of age who had CP since the past 11 - 37 years. Participants were recruited in multiple ways. We contacted people with CP who had previously been affiliated with the research group by email or phone. We also recruited via various pain groups. We emailed post-graduate students mailing lists at UCL, asking people to participate or to send study details to friends and family members with CP.

We conducted interviews in the homes of participants, except SP5 who was staying with her daughter at the time. Each study included a semi-structured interview and a home tour. The interview/observation study which lasted 30 - 45 minutes where people learnt to use the device and then tried it or spoke about how they would use the device in their house for stretches, exercise and everyday tasks around the home, reflecting on how the device could be useful in this context. In a further diary study, five of the participants sent daily reflections via text messages on situations they encountered during the day and how the device could be useful.

Table 11-2. Participant profiles for first home study. Participant Ids are in the format SP#.

ID	Age	Pain area	Pain duration	Working?	Gender	Lives with
SP1	37	Foot	11 years	Student	Female	Alone
SP2	54	Back, knees, groin, hip	15 years	Student	Female	Alone
SP3	54	Knees, shoulders, neck	15-20 years	No	Female	Partner
SP4	37	Lower back	22 years	No	Female	Partner, daughter
SP5	53	Neck, back, knees, hips	16-18 years	No	Female	Partner
SP6	58	Back	29 years	No	Female	Alone
SP7	57	Back	37 years	No	Female	Partner
SP8	26	All over. worst: back, shoulders	17 years	Works from home	Female	Partner, 2 children

Methods

To address the research questions in the first study, we ran contextual interviews in the home using the device followed by a diary study. Both these methods are discussed in this section.

Contextual interviews

Participants were interviewed based on a semi-structured script (see Appendix E) to understand their exercise routines, everyday activities, relaxation activities, and pain management strategies. They were then introduced to the *Go-with-the-flow* device and setup and feedback options were explained. Participants were supported in calibrating the device for a forward reach and they set anchor points for starting position, comfortable stretch and a maximum stretch. After the participants did a couple of exploratory stretches to different sound options, they were asked about their impressions of the device, and their ideas and reflections on how the device could support daily activities and exercise. Where possible, they were asked to use the device to perform the activity.

The design of the initial interview questions about participants' functional activities was loosely inspired by interview elicitation techniques from Petitmengin (2006). We asked participants to demonstrate how they performed certain activities that they mentioned in the interviews or that they performed regularly. We used interview prompts to elicit contextual information about these activities while participants were doing them and asked about how they visualised using the device to support their activity routines and procedures. We did not ask participants to perform any personal or sensitive activities, such as dressing or going to the bathroom. Instead, they were asked about exercise, stretches, and/or relevant household activities that they mentioned during the interview.

Interviews were audio-recorded. Notes were made regarding the activities that were described or performed by participants. To minimise exacerbation of pain or distress, participants were not asked to perform activities that could be taxing or where they appeared to be in pain. With the permission of the participant, still photographs were taken of participants performing physical activity and using various activity-related tools in areas in the home typically used for physical activity. Still images were taken using an instant camera, Fujifilm Instax Mini 90, so that if participants could be given the photo without the possibility of retaining a digital copy if they were not comfortable with the photo. Video recordings were taken of participants exploring the options of the *Go-with-the-flow* device, with their permission.

Diary study

This interview study was followed by a diary study, intended to elicit the connection between the home space, exercise and technology. Participants were asked to send us their reflections of how they would use the device while doing functional activity or exercise in the home. They were also asked to reflect on preferred sounds or other modes of feedback that would be useful, informative and engaging for their daily activities. Participation in the diary study was through sending daily texts or emails over a period of a week. Two participants dropped out of the study.

Interviews were 30-50 minutes long and were transcribed for analysis. The data was analysed using thematic analysis (Braun & Clarke, 2006) as discussed in chapter 4. We continued to iteratively review and refine themes across several weeks of analysis.

11.2.2 Study 2: Longitudinal home study

The longitudinal home study was an *in-the-wild* study (Rogers 2011) to investigate how people would use and appropriate the device when on their own during normal everyday activity. *In-the-wild* studies aim to understand how new technologies may disrupt, support or enhance everyday activities. In this case, we were interested in if/ how the device changed the way people performed activities, in addition to how they thought they would use it or should be using it. The importance of longitudinal studies in situ for mobile devices with multimodal interfaces is highlighted in the literature (Hoggan et al. 2008), as in-depth contextual usage patterns cannot be discovered in a one-off encounter during a control study. Besides, the novelty of a new technology wears off after a certain period of time, and after using it for longer people can critique different aspects of it than they do on a first encounter it (Karapanos et al. 2009). Furthermore, we were interested in understanding the use and suitability of the feedback in

social situations. Next, we discuss the participants for the longer home study and device modifications to allow people to use the device on their own.

Participants

Participants were recruited through multiple channels. People were recruited through the *emo-pain* website, previous contacts of the project team and social media. Potential participants were given information about the study when they contacted us to participate and gave consent for using the device at home. People were instructed on the use of the device before it was given to them for home use.

Four people with CP were recruited for 1-2 weeks (see Table 11-3). All participants were women aged between 34 and 59 years of age and had CP for the last 2.5 – 21 years. It was not intentional that all our participants were women but the male participants had to reschedule. Limitations of the sample are discussed at the end of this chapter. Participants used the *Go-with-the-flow* device in their homes and there were four interviews per participant: on the first day of the study before starting use of the device, in the middle of the study (third or fourth day) and at the end of the study when the device was collected. There was also a follow-up interview after a week to ask people about any other insights they had about device use. Participants were also able to email and phone for support and the researcher was in frequent contact with the participants during the study in case they had any issues with using the device or any technical problems.

Table 11-3. Participant profiles for long-term study. Participant ids are in the format LP#.

ID	Age	Pain area	Pain duration	Still at work?	Gender	Lives with
LP1	59	Back, foot	21 years	Works from home	Female	Partner
LP2	54*	Neck, back, hips	18 years	Community Volunteer	Female	Partner
LP3	43	Back, groin, leg	2.5 years	Not employed	Female	Alone
LP4	34	Neck, shoulder, lower back	6 years	Nursery worker	Female	Partner

Procedure

On the first day, participants were introduced to the *Go-with-the-flow* device and the setup and feedback options for using it. Participants then tried calibrating the device to set anchor points for starting position (S), comfortable stretch (C) and a maximum stretch (M) of the trunk during

* Same as SP5 in short home study.

the reach forward exercise. After the participants did a couple of exploratory stretches to different sound options, they were asked about how they expected to use the device to support daily activities and exercise and what their motivations for using the device were. We asked participants to use the device during activities around the house and during exercise. They were also encouraged to use the device outside the home. Participants were asked to make contact via phone or email if they faced any problems. The device was then left with them for at least a week. One interview was done in the middle of this period to understand how people were using the device and how they thought it was useful and helpful to problem-solve. We then conducted another interview at the end of the study when collecting the device and a final interview or email exchange after another week. Interviews lasted between 15 and 30 minutes. Participants were also given a diary to record their thoughts and experiences of using the device while doing functional activity or exercise, and record where they thought it could be used to facilitate more activity or where it was not useful. We also asked them to think about sounds that would be more engaging and useful for their everyday activities. Interviews were audio-recorded and we took notes about the exercise or activity, the home environment and where people exercised within the home.

Table 11-4. Timeline of study activities in the long-term study

Day #	Study activity	Duration
Day 1	Introduction to Go-with-the-flow device. Instructions on using the device. Sign consent forms Supported calibration of device and device exploration by participant. Elicit first impressions about the device and motivations for using it.	30-45 minutes.
Day 3/4	Interview on Skype or in person about device use	15-30 minutes.
Day 7/14	Collect the device and diary	15-20 minutes
Day 9-21 (Depending on availability after the study)	Follow up interview	10-15 minutes

Modifications to the device for long-term home study

The *Go-with-the-flow* device was modified to enable people to use it in the home. This was done using results from previous studies to make the app easier for people to use without support as we did not want people to be discouraged from doing the study because it was

inconvenient to use. For this study, respiration sensors were not used as they were not easy to use by people on their own. We iteratively tested the device with five people to improve the device and usability before starting the home study.

The changes made to the device included: (i) simplifying the interface, (ii) introducing a remote-control box (see Figure 11-2) (iii) providing t-shirts with pockets on the back for placing the device (see Figure 11-2 (Bottom Left)), and (iv) adding the option for vibrotactile/ haptic feedback. Figure 11-2 shows the components of the kit provided to the participants. The new interface is shown in Figure 11-1 and the options available through the remote are shown in Figure 11-2 (Top Left), Details of the changes are discussed next.

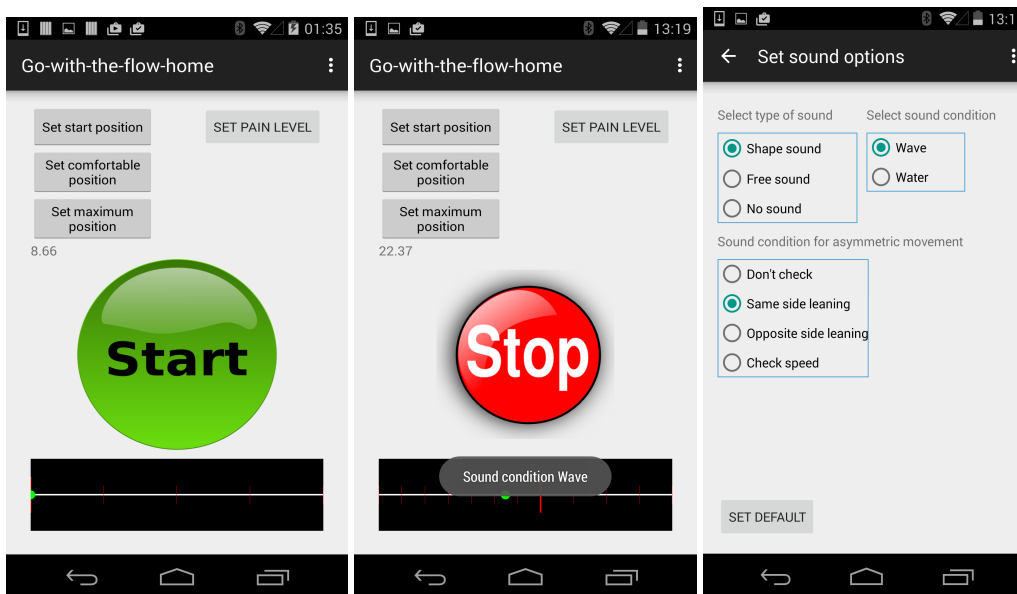


Figure 11-1: Interface for designed *Go-with-the-flow* app for home studies. (Left) The first screen with options to calibrate starting position, comfortable position and maximum position and a start button to start the sound feedback (Middle) When the sound feedback is on, the green start button changes to a red stop button. (Right) The sonification options screen.

- (i) *Simplified Go-with-the-flow interface:* Two simplifications were carried out: (i) only the smartphone favourable sounds were included (*wave, water, wind chimes and no sound*), and (ii) the interface for calibration and app use. Sound and calibration options were available on their own screens respectively. The main screen when running the app now mainly had buttons to set start position, comfortable (C) and maximum (M) positions, a start button to show the user when feedback was on or off and a button to record pain level as shown in Figure 11-2 (Left and Middle). The device continued to record movement even when sound was off and people using the device were informed of this.

We tested the device through different iterations with people with CP before using it in the study. We also tried including an option to tag the functional activity being performed but people found the option too complicated to use.

- (ii) *Device control box*: Since it was difficult to change and set options when the phone was worn on the back, a remote-control box was introduced (see Figure 11-2 (Top Left)) with options to set all the calibration positions, start the sounds on the phone app and change sound conditions. The control box was a cardboard box covered with white labels. The buttons were simple click buttons and were labelled with handwritten labels. The remote was deliberately created as a rough low-fidelity prototype so that users would find it easier to suggest changes to the design of the remote as well as the wearable and app (Datz-Kauffold & Henry 2000). Participants were encouraged to make their own changes and suggestions to the control box design.



Figure 11-2: (Top Left) Newly designed *Go-with-the-flow* Bluetooth remote to control the *Go-with-the-flow* app. (Top Right) Box with remote, camera, and markers provided for the home study. (Bottom Left) T-shirt with pocket for the phone on the back and a pocket cover designed to prevent the phone from falling out. (Right) Diary provided to participants to record their use of the device and thoughts about device use for activity and improvements/ changes they recommend.

- (iii) *Wearable options*: Participants were provided with two t-shirts so that they could wash them if needed. Each t-shirt had pockets stitched on the back for the smartphone. The pocket was made of a DVD sleeve stitched to the back and another DVD sleeve that acted as the cover of the pocket, which could be fastened with Velcro, so that the phone

would not slip out when the person was bending. Participants were asked their size and colour preferences so that they would enjoy wearing the t-shirts. Figure 11-2 (Bottom Left) shows an example of the t-shirt provided with the device. Participants were also provided with a smartphone armband, which they could wear on an arm or leg to try the device in a different position. The tabard used in the previous studies was also provided in case people did not want to use the t-shirt at some stage but still wanted to use the device or even to wear over their own clothes.

- (iv) *Haptic/ vibrotactile feedback*: Haptic feedback was introduced based on focus group studies in Chapter 8 to investigate how people would use the device in certain social and outdoor situations. The device was designed to give vibrotactile feedback instead of sound at the comfortable and maximum positions when the option was selected. The design of the haptic feedback was kept simple to explore how useful people thought it was and how it could be designed. When haptic feedback was on, the sound options would not be available to the users.

Data Analysis

The data collection from the phone sensors was of an exploratory nature to see how people calibrated and used the device over the test period and how the device facilitated transferring their capabilities to functioning. The sensor data was analysed for device calibration over the period of the study. The pain levels were plotted as well to understand if there were differences in people's activity levels based on their reported pain levels. Diary entries helped to make connections between calibrated anchor points and activities being carried out so we could see whether people changed their calibrations based on the activity being performed. Interviews were further used to ask people questions about their calibration and device usage and reflections on device use. We did not analyse the entire sensor data over the duration of the study as it was not possible to draw conclusions about people's activities based only on sensor logs. However, based on the timings of the calibration and the notes in the diary, we extracted a few activity logs for illustration of how people used the device to create strategies for activity and how they used and changed calibration for particular activities.

All interviews were transcribed and a thematic analysis approach was taken to identify patterns and themes (Braun & Clarke, 2006) as described in Chapter 5. In the next section, we discuss the findings from the calibration data over the period of device use and then the findings from the interviews conducted over the both the studies.

11.3 Results from the home studies

In these results, we deliberately distinguish between the terms exercise and functional activity. We use the term exercise for prescribed or structured exercises and stretches, and functional activity to include all types of activity within the home such as cleaning, housework and gardening.

In the first home study, as with our previous qualitative studies reported in Chapter 7, participants reported that most commonly they did functional activity in the home. Our observations and interviews made it evident that the variable and individual character of people's homes, functional activities and routines were different based on various factors such as the size of home and home structures (e.g. number of rooms, presence of stairs), and the number of people sharing the home. People organised their activity in the home to suit available space, time of day, others present in the home (sociality), and place meaning. Space was an important aspect of exercise in the home and included considerations of temperature and light where people wanted to do activity. Attributes of the space such as a doorframe (SP2) or a sofa (SP1) could also be used for exercise. Time was also a consideration: as per our diary studies, people would do their stretches as soon as they woke up in bed (SP8), in the shower (SP3) or next to their bed just before getting ready for work (Chapter 7: P8). Social expectations of space also determined activity in the space, such as a shared living room where people did not want to disrupt their family's routine or were embarrassed to exercise with others present (SP8). This contrasts with others who did exercise with their family (SP4). Some required the privacy of a bedroom (e.g., SP2) or being outside the house (e.g., LP4), and most used functional activity as the main source of exercise. Thus, choice of where and when to do exercises or activity was an important part of doing them at home and required the device to be ubiquitous.

Levels of activity could also change depending on good and bad pain days as discussed in Chapter 7. While participants recognised the importance of performing exercise for pain-management, many highlighted that the home routine and housework left them with little time to do exercise. Instead, many people actively used functional activity as a source of exercise. Fitting exercise or activity with regular aspects of a routine ensured that they would get done.

We first present the profile of usage of the device and of its calibration by the participants of the long home study to illustrate the different strategies of use that emerged to facilitate functioning in the home. We then discuss the themes that emerged from the interviews to better understand these strategies and other opportunities or challenges presented for technology.

11.4 Participant profiles and device usage in the long study

In this section, we first present the data collected from the phone sensors in a story-like way. We then discuss the learning from this data and the strategies people used when using the device in combination with other themes that emerged from the analysis of the interview data and diary studies in the next section.

Use of the device by LP1

LP1 lives with her husband. She is a writer and works from home. Her daily routine consists of her writing work, housework, and stretching and walking. She attends a Pilates class weekly and a private physiotherapist occasionally when her pain gets worse. She also does occasional volunteering work such as working in a community kitchen. During the second week of the study, she went on holiday with a friend and wanted to use the device while on holiday. Her initial motivations for using the device were to increase awareness about her everyday movements in the house and during her work as a writer. She also wanted to use the device to practice stretches and subsequently to improve her range and pace of movement. She also expressed a desire to use the device with her Pilates coach and physiotherapist to better understand from them how to do her stretches when on her own with the help of the device. LP1 is technologically savvy and is familiar with smartphones and apps and excited about new technology. Figure 11-3 shows how LP1 calibrated the device for comfortable (C) and maximum (M) anchor points over the study period. The X-axis of the graph in Figure 11-3 shows the days of the study and the Y-axis shows the bend angles for the trunk calibrated for a forward stretch or bend movement. The secondary Y-axis shows recorded pain levels recorded in the days of the study. The marker points on the graph indicate the calibration of C or M points or pain levels. The lines joining the points highlight the direction of change between these points. The starting point calibration for the trunk bending was nearly the same throughout the study period and so has been removed for clarity.

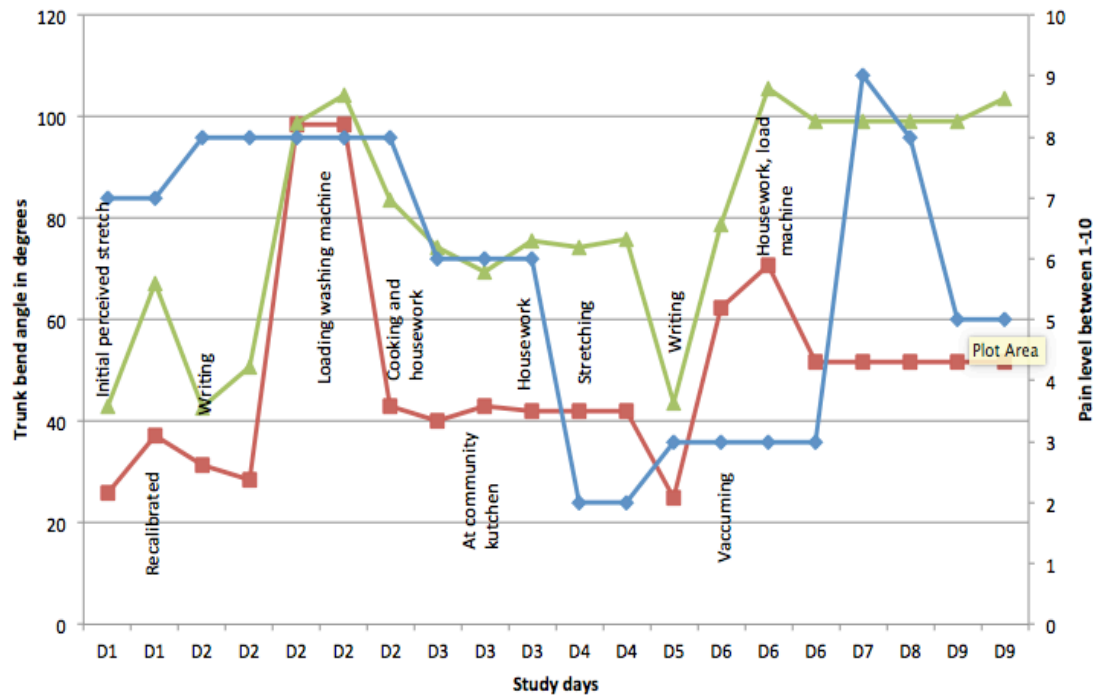


Figure 11-3: Graph showing activity calibration for comfortable and maximum positions and pain levels for participant LP1 over the study period. The x-axis represents the instances of calibration over the days of usage. The markers indicate the values (left y-axis) of the calibration set (red square: comfortable point, green triangle: maximum target). The blue rhomboid (right y-axis) indicates the pain level reported at the time of recalibration. The lines connecting the markers are used only to increase the visibility of the differences between the markers. The vertical text in the graph indicates the type of activity performed after the related calibration. The list of activities were reconstructed from the diaries and interviews.

As the graph (Figure 11-3) shows, LP1 explored the calibration settings extensively, especially during the first few days of the study. On the first day (D1), shown on the graph (Figure 11-3), LP1 calibrated comfortable (C) and maximum (M) points based on her perceived stretching capability. However, when she stretched towards a shelf while doing some housework, the “wave” sound feedback made her aware that her stretching capability was more than initially perceived as she was going past her calibrated M point. This point, marked as *A*, is shown in Figure 11-4 where LP1 recalibrated the device to a higher C and M point based on this feedback from the device.

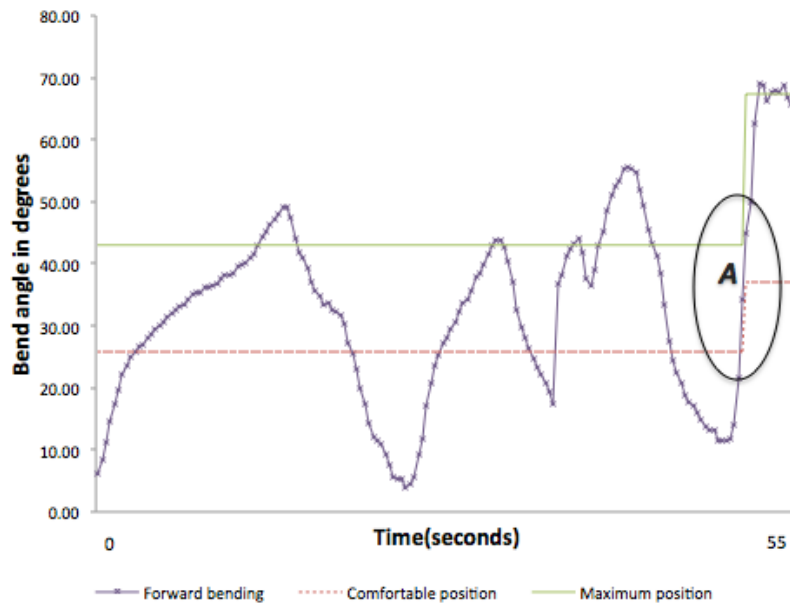


Figure 11-4: Graph showing trunk movement data (purple line) sensed by device during a forward reach activity. The red dotted line and the green continuous line indicate the calibration values respectively for comfortable and maximum positions on D1. At Point *A* on the graph, LP1 increased the values of the calibration to ensure awareness through sound during longer stretches.

On D2, LP1 did some writing work in the morning. The device feedback based on calibration settings from D1 was not responsive enough as the movements during writing were smaller. She recalibrated the device for a smaller space between C and M and, a lower C and M value. When using the device while writing, LP1 realised that she tended to bend a lot while writing, especially over longer periods, and the device feedback reminded her to correct or maintain her posture but the feedback also reminded her to keep moving her back.

Later, on D2, she recalibrated the device to do other housework for a higher C and M (see Figure 11-3). However, when she wanted to load the washing machine, she found that she needed to bend a lot more than her maximum, so the device was not giving her the right amount of feedback. She then actively recalibrated the device to the task of bending to load the washing machine, which meant a much higher value for C and M (see point *B* in Figure 11-5 (Left)) to track and provide information about her bending movement. Figure 11-5 (Right) shows the layout of the room with the washing machine where the participant had to bend to pick up the clothes and also to put them into the washing machine. She took a video of herself doing the activity, which showed how she used the device while engaging in the activity.

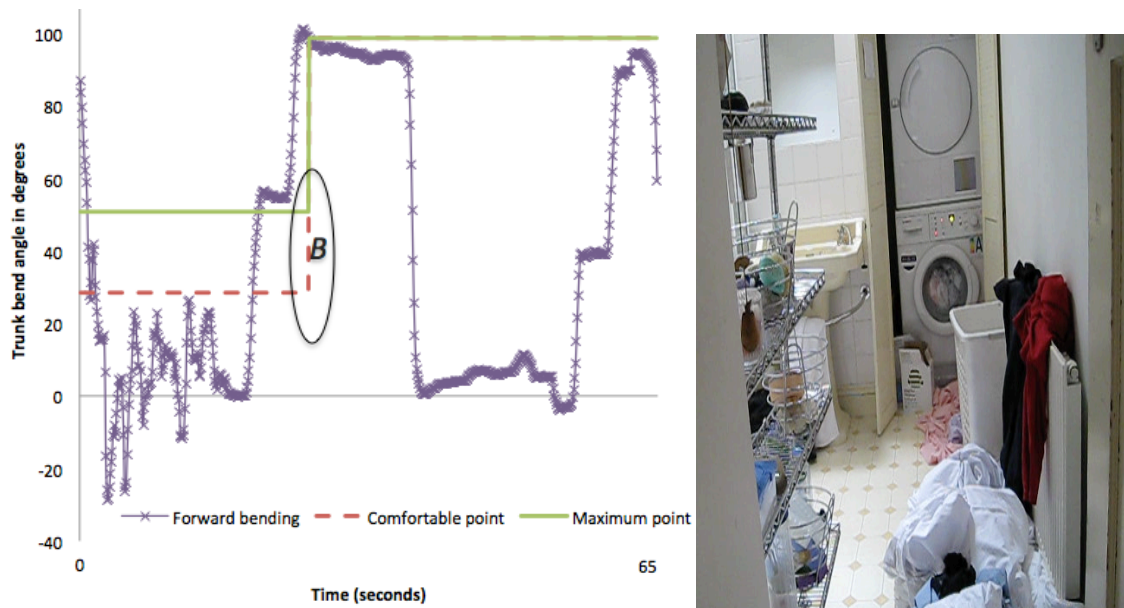


Figure 11-5: (Left) Activity graph showing trunk movement data (purple line) sensed by device for participant LP1 bending to load the washing machine. The red dotted line and the green continuous line indicate the calibration values respectively for comfortable and maximum positions with respect to the calibration on day D2. The calibrations for comfortable and maximum points were increased at point B when the participant realised she needed to bend a lot more compared to the calibrated maximum. Hence the readjustment ensured awareness of the movement. (Right) Layout of room with the washing machine.

LP1 lowered the calibration of C and M for cooking and tidying the kitchen based on the feedback because this activity required less bending. On D4 and D5, LP1's calibration levels for cooking and housework were similar. However on D5, the app was recalibrated again to a lower C and M because she found the lower values more useful for writing.

On D6, the app was recalibrated for doing household tasks such as loading the washing machine and vacuuming. The calibration for loading the washing machine was done in a similar way to the earlier calibration on D2 as LP1 felt confident with this calibration. As LP1 said, *"Once calibrated, it made me more confident when doing things like loading the washing machine - because I'd already proven to myself I could do it. As I said before, it's this proving to myself I can do this that I found most helpful."*

On D7 and D8 the app was not used much as LP1 was unwell and she was also going to go on holiday on D9, so she wanted to *"take it easy"*. While LP1 intended to use the app on holiday, she could not because she got an insect bite between her shoulder blades. However, she felt that having used the device in the week before, the feeling of the device on her back was *"imprinted in my memory"* making her more conscious of her posture and confident in doing movements, which was remarked on by her friend as well.

Use of the device by LP2

LP2 lives with her husband and often visits her grown up children who live in a different city. During the latter part of the study she was distressed due to illness of someone close. LP2 is at home on most days and does occasional volunteer work. She had the device for two weeks but used it actively and filled in the diary only in the first week. Her daily routine consists of some stretching and housework and she does weekly gardening. Her initial motivations for using the device were to explore her activities in the house and to practise her stretches. LP2 is familiar with smartphones and apps and uses her smartphone regularly. Figure 11-6 shows how LP2 calibrated the device for C and M anchor points over the period of the study. The X, Y and secondary X axes are the same as for the previous graph. The calibration for the starting point (S) was nearly the same throughout this period and so has been removed for clarity.

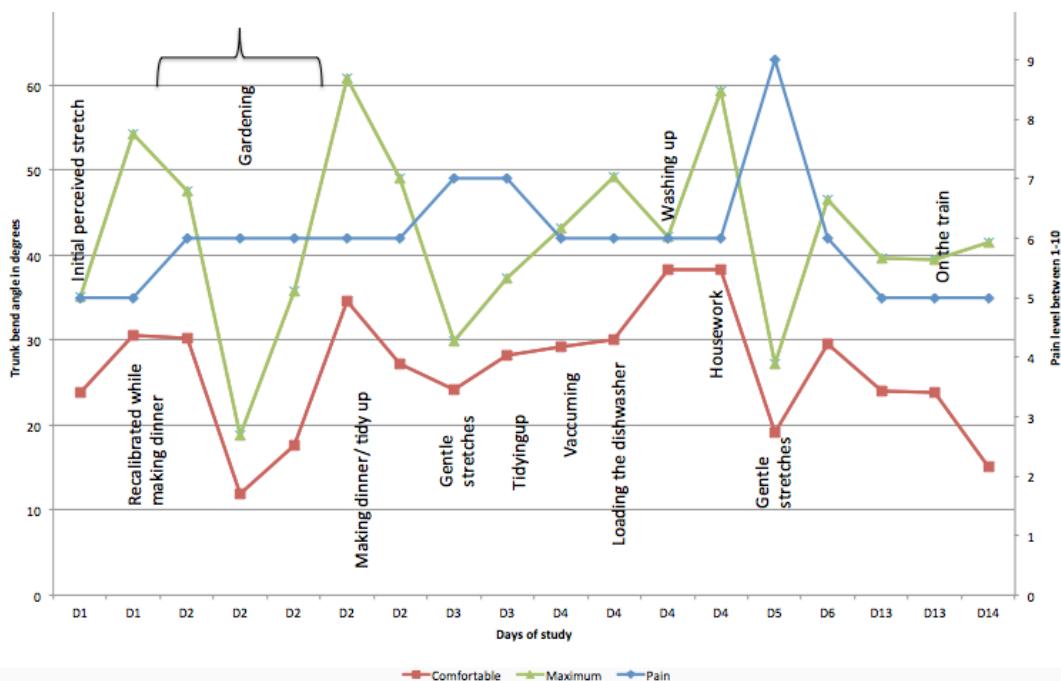


Figure 11-6: Activity calibration for C and M points and pain graph for LP2 over the study period. On day D2, there were 3 different calibrations while LP2 was gardening and these have been shown as grouped together by a bracket over gardening in the graph. The x-axis represents the instances of calibration over the days of usage. The markers indicate the values (left y-axis) of the calibration set (red square: comfortable point, green triangle: maximum target). The blue rhomboid (right y-axis) indicates the pain level reported at the time of re-calibration. The lines connecting the markers are used only to increase the visibility of the differences between the markers. The vertical text in the graph indicates the type of activity performed after the related calibration. The list of activities were reconstructed from the diaries and interviews.

On D1, as with LP1, LP2 started with a lower starting calibration for C and M as shown in the graph. However, when reaching in shelves in the refrigerator for ingredients, she became aware based on the “wave” sound feedback, that her range of movement was higher and recalibrated C and M as shown by the next points on the graph to try to stretch to this M value.

On D2, LP2 did gardening with the device on her back. On D2 there is a big variation between C and M in the graph based on the strategies and movements adopted during gardening. LP2 reported that she was exploring the device, starting with recalibrating the M value of the device for gardening tasks which required bending. However, LP2 first changed her strategy while doing weeding. She felt that she was not getting as much feedback as she needed for the smaller space. She lowered C and M calibration for a much smaller space of controlled movement while kneeling to do some weeding. Differently from LP1, her rationale was to use the feedback for a more responsive lower calibration to ensure she stayed in the defined space and did not bend more than the maximum. At the same time, she wanted to ensure she kept moving because staying still worsened her back pain especially over longer durations. She also changed the feedback during this time to windchimes as this sound condition was designed to only give her information about moving within the defined space but position within this space was less important to her. Also, she found the sound of windchimes pleasurable and companionable. Later, she twice increased both C and M calibrations for gardening tasks that needed a greater range of movement. The highest M position was for bending to tidy up garden waste since the space of the movement increased because of the demand of the activity. This indicated there was a difference in calibration and feedback requirements when people did activities for a small or long period of time and also the calibration values were different based on stretching forward or bending movements. Later the same day, LP2 lowered the calibration for cooking dinner similarly to D1. This indicated that once people had used a task for calibration, they could reuse it to calibrate based on activities they wanted to do.

The calibrated C values across the graph (see Figure 11-6) changed a lot across the week. One of the reasons was that the activities that required bending (e.g. picking up garden waste) were calibrated differently with higher C and M values compared with the activities that required stretching (e.g., weeding).

On D3, LP2 woke up with high pain and tightness in her back and she lowered the calibration for C and M to do gentle stretches to ease her back. Later in the day she raised the calibration for C and M moderately to facilitate chores around the house such as tidying up and dusting, however the calibrations were much lower compared to previous days.

On D4, LP2's pain level was lower and she used the device for tasks such as vacuuming, doing the washing up, general housework and making dinner. The highest calibration values for M were for loading the dishwasher because the range of movement was higher for bending from the sink to the dishwasher. However, the range between C and M was narrowed when putting the washing on an airer as this activity did not require much bending or reaching forward.

However, the last calibration is much higher and according to LP2 she recalibrated to load the washing machine which involves bending down, which she calibrated as a different movement.

On D5, LP2's pain levels were much higher and so she used gentle stretches to ease her back. From D6-D14, LP2 occasionally used the device, but she did not log her activity in the diary so it is not clear what activities the device was used for except for D13 when she reported that she took the device on a train journey and used only vibrotactile feedback. She calibrated the vibrotactile feedback to a small range of movement because she wanted it to support her in stretching occasionally upto that calibrated point. Unfortunately she could not feel the vibrotactile feedback from the device very well because of the placement of the phone and so she used wave tones for a while but switched it off quite quickly because she was preoccupied by personal problems and did not want to focus on the device.

Use of the device by LP3

LP3 lives alone and does not work at present. She has relatives and friends who visit her often and thus has an active social life. Her daily routine consists of housework (cooking, cleaning, tidying up), occasional shopping and visits from friends. Her initial motivations to use the device were to be more aware of her body, movements and posture, and to remind her to change posture or to not adopt positions that caused her pain. LP3 is familiar with smartphones and apps. LP3 was meticulous in filling out her diary with tasks she performed using the app during the study. There were many recordings on the app when LP3 was testing the device and trying to calibrate it and she highlighted these times in her diary. As with the other participants there were also recordings where she was putting the t-shirt on and taking it off while the app was running.

To avoid taking the t-shirt on and off due to problems with her right arm, and to explore a larger range of activities using the app LP3 grouped together activities that she would not usually necessarily carry out at the same time. Figure 11-7 shows how LP3 calibrated the device for C and M anchor points over the study period. The graph elements are consistent with previous graphs for LP1 and LP2 in this section.

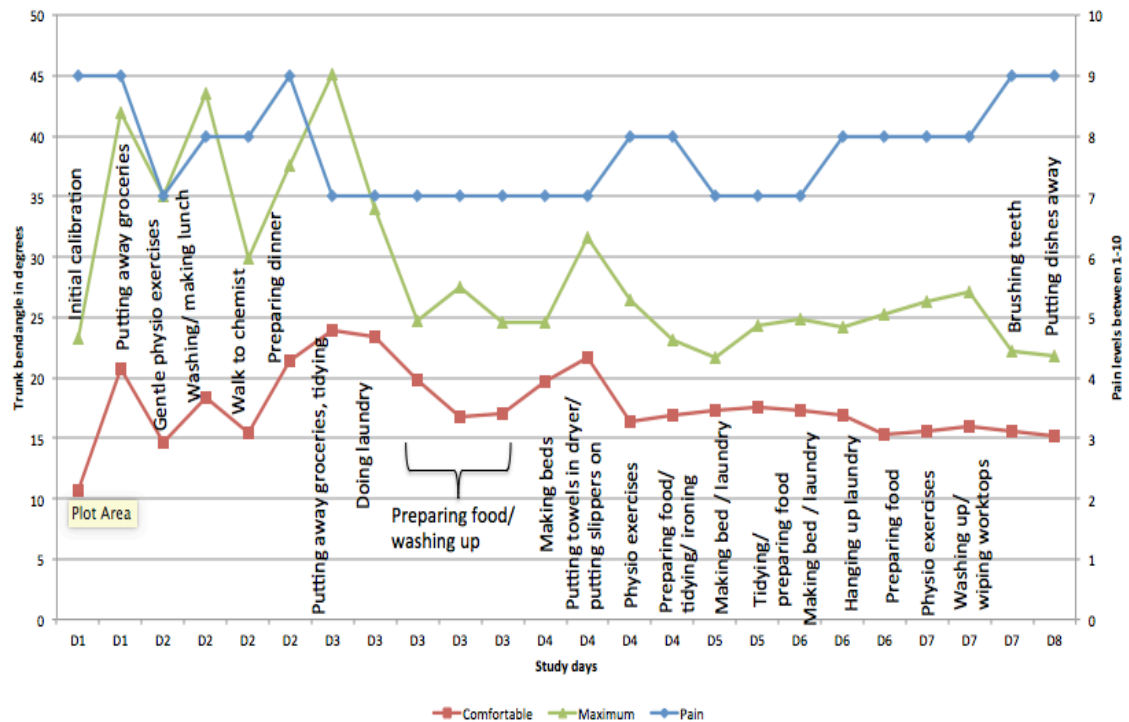


Figure 11-7: Activity calibration for C and M points and pain graph for LP3 over the study period. The x-axis represents the instances of calibration over the days of usage. The markers indicate the values (left y-axis) of the calibration set (red square: comfortable point, green triangle: maximum target). The blue rhomboid (right y-axis) indicates the pain level reported at the time of re-calibration. The lines connecting the markers are used only to increase the visibility of the differences between the markers. The vertical text in the graph indicates the type of activity performed after the related calibration. The list of activities were reconstructed from the diaries and interviews.

On D1, LP3 had significantly high pain levels (around 8/9) and she reported this hindered her activity levels. She did an initial calibration to use the app while pottering in the kitchen and doing washing up. However, she increased both C and M when she started putting away groceries because the range of movement required was much larger to take groceries out of bags and put them away, which required bending movements. This was also the reason for the large calibration of C and M on D3, when LP3 put away groceries, also the highest calibration of C and M of the week for her. She also found it was convenient to use the phone device by tucking it into her back support which she was using on this day.

On D2, LP3 used the phone to do gentle standing physiotherapy exercises such as stretching the back. She felt that she could not do most of her lying down physiotherapy exercises because of the presence of the device on her back. She decreased both C and M compared to the settings for the functional activity on the previous day for the physiotherapy exercises. Later the same day LP3 used the app while going for a walk to the chemist; one of LP3's motivations for using the device was to avoid leaning on her walking stick for support while walking and she wanted to explore this with the phone app so she reduced the calibration to a lower range of C and M to get sound feedback for this smaller range of movement by exploring the device.

Later LP3 raised C and M while preparing dinner for the larger range of movement required such as to reach into cupboards and to get ingredients from the refrigerator. At this stage LP3 commented in her diary that the app was definitely helping “*to remind me to keep movements more controlled (posture, muscles engaged, etc.)*” because of the small intervals of sound feedback in the “wave” condition, which helped to control pace of movement. LP3 increased calibration of C and M again while loading the tumble dryer. For all other tasks during the evening such as preparing food, tidying and washing up, she set a lower calibration to keep her movements within a smaller range of movement. This was because a few movements had really aggravated and increased her pain, such as getting up too quickly from her chair and having to lean over to shut a window. On D4 and D6, LP3’s pain levels were much higher so she calibrated her C and M values to lower values to keep her activities controlled.

LP3 also tried to use the phone on her leg to remind her not to tuck her legs under when she was sitting in a straight chair while sitting at her desk. However, she could not get the sounds to work. We later realised she had put the device the wrong way up and so the calibration did not work and this is a usability issue with the device that needs addressing. However, she reported that just the presence of the device on her leg made her more aware of her leg’s position.

For LP3, there are two main interesting things on the graph (see Figure 11-7). First, she recalibrated many times over the study period. This was because she used the device multiple times during the day and recalibrated every time she started using the device. She also recalibrated according to the functional activity being performed and used the feedback to keep track of her stretching. However, if she felt her pain increasing, she either stopped using the device or recalibrated it to a lower value. Second, the range between her calibrated C and M values is very large in the graph. This was because, for her M was the point of interest and she calibrated C as just an intermediate point often halfway between the two. This was because LP3 felt that she was not target-driven, and just wanted to ensure she was maintaining a stretch rather than increasing her range of movement so two anchor points were sufficient for her.

Use of the device by LP4

LP4 lives with her partner and works as a nanny. Her daily routine consists of looking after a child, cleaning and tidying, making meals. She tries to do stretching exercises between tasks. Her initial motivations to use the device were to learn more about her movements and to understand if controlling her movements or being aware of them could help to reduce her pain. LP4 is familiar with using a smartphone and apps. Figure 11-8 shows how LP2 calibrated the device for C and M anchor points over the study period. The graph elements are consistent with previous graphs for LP1, LP2 and LP3 in this section.

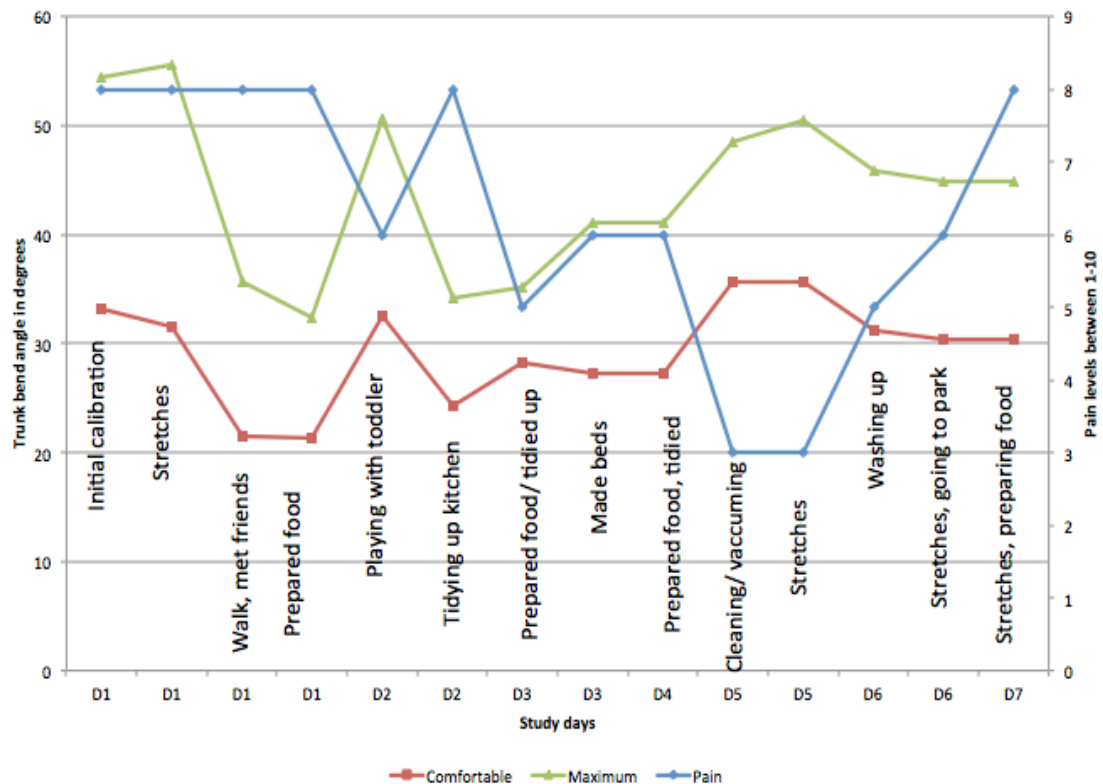


Figure 11-8: Activity calibration for C and M points and pain graph for LP4 over the study period. The x-axis represents the instances of calibration over the days of usage. The markers indicate the values (left y-axis) of the calibration set (red square: comfortable point, green triangle: maximum target). The blue rhomboid (right y-axis) indicates the pain level reported at the time of re-calibration. The lines connecting the markers are used only to increase the visibility of the differences between the markers. The vertical text in the graph indicates the type of activity performed after the related calibration. The list of activities were reconstructed from the diaries and interviews.

Unlike the first three participants, LP4 started with a high initial exploratory calibration on the first day of using the device despite a high level of pain. Next, she recalibrated to do her stretches, she decreased her comfortable stretching point because her pain was high and stretching was proving difficult but raised her maximum point. She explained, “*if I try to stretch more, I feel like it will help my back to get better, because I have pain but I have stiffness too, which stretching can sometimes ease!*” She also used the sound feedback in the “wave” condition intervals to pace her stretching.

LP4 recalibrated to a much lower C and M when she went for a walk and to the shopping centre to meet friends. This was a 25-minute walk during which she did occasional small stretches to ease her back. Her reason for the lower calibration was an increasing pain level, which made her feel that she needed to do smaller, more controlled stretches. This smaller calibration gave her more feedback for a smaller space of stretch but after some time of using it, the feedback felt overwhelming and she reported that she had to lower the volume considerably. At this point she also tried the vibrotactile feedback but did not feel it very well. She also discussed the device and feedback with her friends and used it while she was with them. Later on D1, she made

dinner and tidied the kitchen and lowered the M calibration further – she calibrated the M according to how much she needed to stretch to get her plates out.

On D2, LP4's pain levels were much lower during the day and she used the device while playing with a toddler and taking the toddler to the park where she needs to do a lot of bending and stretching, hence high values of C and M. By afternoon her pain levels were much higher as Figure 11-8 shows. When she had to tidy up the kitchen later that day, she calibrated C and M in the same way as D1 when she was cooking. This reiterates (similarly to other participants) how people reuse successful strategies which can potentially reduce the decision-making of how much to stretch based on functional targets, for good and bad pain days.

D3 and D4 were LP4's days off work. On D4 she used the device to do some housework including making beds and preparing food. LP4's calibrations for tidying up were similar to when tidying the kitchen on D1 and D2. On D4, LP4's pain levels were much lower and she used the device while doing some vacuuming and cleaning the house and did a lot of stretches.

On D5, LP4 was working again and used the device when she took the toddler to the park using it while pushing the toddler on the swing and playing in the park. She used the feedback to maintain awareness of stretching her back while she played with the toddler.

LP4's graph shows highly variable pain levels throughout the week and had fewer calibrations because she was working for most of the week and had fewer opportunities to use the device. Her diary was also not as detailed as the first three participants for the same reason.

In the next section, we report results of the qualitative analysis of interview and diary data. Before that, we summarise here in Table 11-5 the strategies that emerged from the sensor data analysed above for reference. These strategies are also clarified in the themes that emerged from the qualitative interviews in the next section.

Table 11-5: Calibration strategies that emerged from device use to enable functioning

Emerg Self-Calibration-based Strategies to enable Functional Activity		
Situation	Strategy	Purpose and Mechanism
People's perception of capability is lower than their real everyday functional ones	Using sonified exercise spaces (SESS) self calibrated to perceived capability while engaging during non feared everyday functional activity	Psychological progress: Increased self-efficacy and confidence. Sonification structure (through provided information) increased awareness of capabilities when these fall beyond boundaries of SES. This leads to reconsidering calibration.
Functional activity	SES calibrated to	Psychological support: Increased sense of

Emerg Self-Calibration-based Strategies to enable Functional Activity		
Situation	Strategy	Purpose and Mechanism
requires a person to go beyond physical or psychological capability	functional activity, that is beyond perceived capability	control, provides information to facilitate pacing, increases awareness of body movement, etc. Note: Higher number of anchor points to provide more information beyond perceived capabilities Strategy risk: could increase anxiety or sensitisation to sounds associated with pain if person becomes over anxious
Functional activity of long duration (but within people's perceived capabilities)	Activity range within SESs calibrated to minimum capability needed.	Sonification as a co-supervisor: <ul style="list-style-type: none">- Avoid overdoing and increased pain- Richer information to facilitate pacing and awareness (e.g., including awareness of not moving) * Continuous sound (non-informative) as a reminder to keep moving and companion
Functional activity of short duration and not particularly demanding	SESs not calibrated (just sonification) or only calibrated to maximum target to be avoided	Practicing: To introduce challenge, to work on improving capability But also to avoid overdoing * Continuous sound (non-informative) as a reminder to keep moving and companion
Perceived capabilities are sufficient to perform the functional activity at hand	SES self-calibrated to range of movement required by functional activity i.e., lower than perceived capability range.	Practicing: Use increase movement information to improve movement quality rather than extent of movement But also: To avoid over-use of resources or maintain the same position for too long
	SES self-calibrated beyond range of movement required by functional activity i.e., equal to perceived capability range.	Practicing: To use functional activity as an opportunity to exercise more
A demanding functional activity requiring full attention or that could lead to distraction	Use of (aural or vibrotactile) cued feedback rather than SESs sonification	Supervisory role to remind of pacing and avoid overdoing Notes: Used in social situations or where continuous sound is no longer required or becomes annoying or where sound interferes with activity

11.5 Results of the interview and diary studies

The device usage profiles presented in the above section show the emergence of a set of strategies to facilitate functional activity. They also show how participants' differing motivations have led to similar calibration strategies but also to different ones. However, while people felt strongly about what suited them, these things differed across our participants. The main strategies are listed in Table 11-5 and are discussed here within the 6 themes that emerged through the two studies, reflecting on how people used Go-with-the-flow device in the home: (i) providing people with a handle to reengage and manage capabilities, (ii) using sound in a co-supervisory role to overcome barriers, (iii) disrupting routine and challenging habits, (iv) providing control over the environment, (v) opportunities for automatic detection of capability, and (vi) facilitating pain management in social situations. These themes are discussed below. We also highlight the affective dimension to each of these themes within the discussion of each, but the psychological elements are implicit in the design of this device and the aspects we have highlighted previously may not be discussed again in detail.

11.5.1 Providing people with a *handle* to reengage and manage capabilities

The patterns of use of the device that are reported in Table 11-5, show how Go-with-the-flow can make people more aware of their body and movement and provide them with tools to manage their resources and recognise their capabilities. While people used the device for functioning in different ways, there were clear, common patterns that while motivated by different aims led to different uses of calibration that are described in the table above.

Once participants had calibrated the device to their movement capability, they explored the sound feedback to check that it reflected their movements and that the sonification changed at the right time. This built trust in the information provided by the device and the association of the feedback with their own movement and body provided an enhanced awareness of their body. This raised awareness made their body reappear from behind the pain, and helped them to attend to their movements and capability rather than to their pain. In effect, the device provided a *handle* to their capability, allowing them to make effective use of their own resources.

The first point of providing a *handle* was at the exploration stage, where the person explored his/ her capability to do movement and set the calibration anchor points. These points could be set by the person on their own and be completely self-directed or could be supported by a physiotherapist/ coach or trusted other. Users could reset the calibration at any point if they felt that their capability had changed. This gave them maximum control over their movement and

provided a tool they could use to better understand their bodies and abilities in different contexts, thus allowing them to build confidence in their ability to self-direct activity.

In the first short home study, people envisaged calibrating the device with respect to a functional task they wanted to achieve and then using the sound feedback to practise the movement. However, wearing the device during functional tasks gave new insights into how participants used their body in different activities and different contexts. For example, in the long study, when using the device on her own, LP1 first calibrated a forward reach stretch based on her perceived capability to stretch. When she started using the device for functional activity and reached for the shelf, the sound feedback made her aware that her actual capability for such a stretch was much higher than she had anticipated and calibrated for and she had been avoiding the activity because of fear of pain. This strategy can be seen in Table 11-5. This is congruent with the literature that shows that people may be afraid of making certain movements but find they are able to do them in a different context when they are not focused on it (Rainville et al. 2011). LP1 explained,

"The first thing I realised after calibrating the device, was when I went to get something from the shelf, I went past my calibrated maximum without thinking but the sound told me that I was beyond my maximum. So, I can do more than I think I can. It's the fear that the pain will kick in that holds me back. But the sound immediately gave me that insight into the way I move when I am thinking about it and when I'm not."

When designing the device, we had in fact anticipated that people would use the device the other way around by calibrating for an everyday functional activity and practising through exercise. Two types of calibrations emerged from our study: (i) calibration for exercise (CE) according to perceived capability, and (ii) calibration for functioning (CF) according to not only to perceived capability but also to the activity space. People indicated that there might be a subspace that was more important for some reason and needed more information (e.g. LP1's recalibration of writing where the initial bend angles were more important: see Figure 11-4). When the difference between CF and CE (CF-CE) was positive, then lack of sound could trigger anxiety through lack of information. When CF-CE was negative, the lack of feedback because the person was moving beyond his/her calibrated range could raise awareness of higher movement capability and increase confidence in movement.

Participants found that just using the device while doing functional tasks could enhance awareness of movement, especially when people are not focused on it. For example, LP3 said, *"Just pottering around and hearing the sounds, you realise you are moving and stretching a lot more than you think you are!"* However, constantly having the sounds on could get a bit

overwhelming after a while for some participants. LP3 suggested that she could have used the option for vibrotactile feedback in such cases.

Another way that the device provided a *handle* to operate the body was by increasing awareness of not moving. For example, LP4 became aware of being very still while washing the dishes because she got no sound feedback even though the device was on her back and switched on to an audible sound condition. LP2 also reported this in her diary for times when she was brushing her teeth or washing the dishes. While the absence of sound itself also acted as a cue, LP2 felt that a different sound cue or vibrotactile feedback to make her aware of being still at a particular angle for some time would also be useful to her.

LP2: "Cleaning teeth - leaning over basin. Leaning at e.g. a 30 degree angle for a sustained period (even two minutes) can be worse than leaning forward to retrieve something."

However, for some people even the constant bending and straightening in a task (e.g., to wash dishes) could be painful and this emphasised the need for people to be able to sonify their own personal strategies. For example, SP6 in the first study said in her diary,

"[Standing] in this slightly bent over position and this repetitive bending forward and back motion [while doing dishes], leads me to experience pain in my lower back and groin area and both hip joints."

People derived different meanings from the sounds provided by the device according to context. In some contexts, they used the sounds as a companion to overcome feelings of being isolated. For example, LP3 said, *"I used it while gardening and because I was moving constantly in different positions, it was very pleasant to have the sounds as company as I pottered around. It made me aware but also was a pleasant companion."* While LP3 used the *wave* sound as information, in some cases she felt the continuous sound of *wind chimes* provided by the device was useful as it encouraged movement in general without focusing on targets. She felt that using a favourite song or soundtrack would be quite pleasurable in such situations, where the song would play only as long as the person was moving, thus encouraging movement.

People used the Go-with-the-flow device as a *handle* to create different strategies for exercise and function in the home and beyond. For example, people found that they discovered strategies that they could use to transfer what they did during exercise to functional activities. Thus the device helped them in generalising certain movements to different contexts, which may have been anxiety-provoking as discussed in our studies in Chapter 7. An example of this was LP1 using a Pilates movement to load the washing machine:

“It’s probably good for my back to lean further forward but I’m hesitant about doing it and I find reaching for the washing machine painful. However, I realised when doing exercise with the device and hearing the sounds, I could use the roll-down [Pilates exercise] to load the machine, which actually relieves my back. And because I do the roll down all the way down when doing exercise and I’m nowhere near the bottom of the roll down when this tells me that I’ve reached my maximum. So, it’s useful for trusting my body more than I do. And I’m sure I’m not leaning forward because I’m worried that it’s going to hurt.”

The device was also able to provide users with ways to adapt feedback to their own movements. For example, people used different strategies for calibrating for stretching movements and bending movements (for e.g., LP2’s data when stretching for weeding and when bending to pick up garden waste). Also, people used different strategies for calibrating when they were expecting to do a task for a longer period of time (e.g., smaller interval in LP1’s data when writing and LP2’s data when weeding).

Different strategies were also employed for target vs. non target-based movements. For example, LP4 calibrated the device to stretches and used the activity of pushing the swing with the toddler she looked after to do reach forward exercises. Within this activity, there was no target she needed to achieve but the device supported her in practising the required movement. In other cases, participants used the actual activity target to practise or calibrate movements.

Participants were not satisfied with using the options provided on the device to build strategies and discussed modifications that could help them further personalise their strategies. For example, people had different preferences for the number of calibration points that they wanted to set for the device based on their motivations for using it. LP2 preferred having just two anchor points instead of the three provided with the device. She felt that using the two points would be enough to allow her to maintain her mobility which was her aim, as she was not interested in improving her range of movement. She explained, *“I think from my perspective, two [anchor points] would probably be enough because I’m not looking to work to a target, I’m just looking to maintain my mobility.”*

On the contrary, LP1 wanted the device to suggest additional points to raise awareness of her actual capability and also to take over the function of suggesting increases and overcoming her own fear and hesitation in making those increases. LP1 explained,

“You set your initial point, your comfortable position, your maximum position, and have [the device] feedback. When you’re doing exercises or movements, if you are consistently reaching another point, have it save that and feed that back to you.”

[...] Now if the device spotted that we consistently get to this point beyond our maximum, having it store that point and giving you the option to see how far you can go with a very different sound, [...] something that is a kind of 'well done' sound that could be really helpful for people in recalibrating it next time. So [...] you can opt to set it to that further maximum. And then you can get beyond that!"

Some participants felt that they could use the device with a physiotherapist to develop strategies and calibrate the device and use the calibration to practise the movement at home. However, a physiotherapist interviewed as part of the previous focus group felt that the context in which an activity is performed could influence the calibration and hence it may not always be useful to calibrate a movement in hospital settings to be used in the home.

11.5.2 Using sound in a (co) supervisory role to overcome barriers

In other contexts, especially when there was high cognitive load, participants felt that sound was reassuring and informative and used it in a supervisory capacity. For example, people felt that they could use the device to practise suggestions given by physiotherapists such as “*not leaning too far back*” (LP3) when stretching. Others reported that they were reminded to: “*keep changing position*” and “*do more stretches when standing for long periods*” (LP1), “*remember not to tuck legs under*” (LP3), “*sit straighter*” (LP2) and “*move while doing the dishes*” (LP2, LP4). In this case, the device could provide “*a second set of eyes*” (LP3) and help people to have “*more control over their movements*” (LP2). LP2 explained, “*what it is helpful with is almost like there's a like a bit of that kind of 'physio on your shoulder', type of thing, to tell you or to remind you about doing that movement.*”

The supervisory role of the device could also be used to increase awareness of adapted movements or protective habits that people had developed. For example, LP2 used a walking stick and had developed a habit of leaning over her stick when walking. She had asked family and friends to highlight such leaning if they were with her but she had difficulty with spotting it when she was on her own. She explained: “*if you're walking with a stick and you lean forwards kind of too much, then that can trigger pain. So kind of things that remind you: I've often thought that it could be really handy.*” LP1 felt she needed similar support when she was writing for long periods of time.

Similarly to physiotherapists in our earlier studies, the device also shifted people's focus to pleasurable sensations such as the sound of the tones or windchimes. For example, SP7 said while trying the *Go-with-the-flow* device, “*I wouldn't just bend for exercise, I find bending uncomfortable and painful. But I do need to bend – my dishwasher, washing machine, cleaning*

my bathtub all need me to bend – and these sounds [from the device]: they may help me to focus on them [sounds] instead of the pain and that is helpful”.

Further, because the *wave* sound was designed to provide feedback for even the smallest movements and to provide information at every point, people used it to learn movements and become more aware of how they were moving, such as pace of movement. This was emphasised in our findings in Chapter 8. The reward provided by small sound intervals for feedback in the *wave* sound, made people feel that they were moving more and that it was worth doing the activity. LP3 said, *“It’s just nice to hear the sounds, even when I am only doing small things around the house I feel like I am achieving something”.*

11.5.3 Disrupting routine and challenging habits in long-term use

People introduced changes in their usual routines based on feedback from the device. Both LP2 and LP4 introduced stretches when washing up the dishes and felt that doing so would reduce the stiffness they felt after the task and at the end of the day. LP4 reported that she felt less stiff after doing dishes if she incorporated stretches while doing the activity:

“I don’t realise that my muscles are starting to be stiff until I am in pain, and then it becomes really difficult to relieve the pain.”

Many participants felt that the device could help them to form new habits. In some cases, even if participants switched off the sound feedback from the device because they wanted to focus on something else, they found that just the presence of the device between their shoulders made them more aware of their posture or movement. LP1 said,

“What I also found really interesting is that when the thing had switched off, just having it between my shoulder blades made me more conscious of my posture.”

A week after they had stopped using the device, people reported continuing with such new habits related with posture and movement, not just because of the initial awareness built by the sound feedback but because of reflecting on the new awareness and making changes (such as interspersing stretches in activity). They reported that that they felt more *“body-aware”* (LP4) after the study and felt that the feedback about existing habits, which they could discuss with their healthcare providers or choose to change was very useful.

People felt the device was useful because it not only made them more aware of their movement but also highlighted avoidance and supported them in overcoming their fear of moving especially in movements that caused anxiety about triggering worse pain.

“It’s telling you that you have more mobility than you think you have...” (LP1)

However, to form habits behaviours need to be repeated over a long period of time. Even though our studies were short to judge if habits had been formed, participants reported feeling more confident and comfortable in movement and having greater awareness of their body. LP3 said,

“My friend said you know, something about you has changed. You’re moving so much better. And I feel that, I do. I don’t think as much because I know how much I can do”.

When the device was used over an extended period during our long study, the nature of use changed over time. For example, in the beginning the continuous feedback increased awareness of body movement during exercise and function and using the device functionally allowed people to generalise that learning across activities and contexts. The use of feedback also changed through the study week. Continuous sound feedback was considered most helpful when exploring and building new movement to build awareness of movement. Using the continuous sound feedback to generalise movement to different situations was helpful to address barriers to movement in CP (see Chapters 2 and 8) such as to alleviate anxiety (as in LP1’s example with the washing machine).

Some participants wanted to use the device for a longer time but the pitches in the wave sound could become annoying after the device had been used for a while. LP3 reported that people with CP can become more sensitive to certain sounds especially over long periods of use. This finding resonates with the concept of sensitisation in the psychology literature, where repeated exposure to a sound makes it seem unpleasant (Ji et al. 2003). LP3 suggested that the pitch of the wave sound should be lower so a more bass instrument should be used as *“after a while the sounds get quite annoying”* (LP3). One participant (LP4) suggested that instead of the tones going up in pitch, the same note should go up in volume. All participants liked the water sound and found it more relaxed and *“less annoying”* than the wave sound after a few days of use but preferred using the *wave* sound because the information and transitions between movements and notes was clearer. Participants suggested two alternatives. First, after using the device for a while, on learning/ developing an understanding of a certain movement, people could switch to cued feedback (feedback at certain predefined points during the movement) rather than continuous feedback. Such cued feedback could be sonification at the point of achieving anchor points set during the calibration or performing different movements chosen by the person to increase awareness (such as moving asymmetrically or too fast). A second suggestion was to use vibrotactile or visual feedback instead of sound if a person had started to feel tired listening to the sounds or was in a situation where sound could be disruptive.

11.5.4 Providing a sense of control over the environment

While most of the device use was focused on awareness of their own body, some participants also used it to identify aspects of their environment that could be changed for better functioning. For example, LP3 used the device to reorganise her space to function more efficiently.

“Realised my kitchen towels are hung too low, which necessitates regular bending. Now hung higher.”

While this could also be viewed as an avoidance strategy discussed in Chapters 2 and 7, LP3 reported that reorganising her space was a strategy to conserve energy for other more enjoyable things that she generally found herself too tired to do. Our physiotherapists also reiterated on several occasions in previous studies reported in Chapter 8 that pain management was not about pushing past pain but about moving often and building slowly. This kind of reorganisation to avoid overdoing activity could help people to avoid overdoing certain movements that cause pain after being done repeatedly.

This contrasts with some of the other participants, who deliberately use the setup of their environment to make tasks challenging, such as keeping things out of reach so that they would have to stretch to use them (e.g., SP3). However, one difference between the two cases is the regularity with which the task needs to be performed. If a mundane task is performed repeatedly, then people may find that they are spending a lot of energy in carrying out the task, and reorganising to make it easier may work better for them so that they can focus on other more important tasks.

11.5.5 Opportunities for automatic detection of capability

Most people found that the sonifications were reassuring and engendered a feeling of trust in their body capability. Insights from the device on their movement led some participants to suggest that after the device had been tracking their movement, it could automatically recalibrate based on the tracked capability, rather than the user self-calibrating, especially if people were avoiding the activity because of low confidence or fear. LP1 said, *“So other than you recalibrating and trusting your own bravery, you have the device tell you that you are doing better than you think.”*

However, there could be some problems with this approach, which need to be addressed. As LP3 found that stretching further in functional tasks did not always indicate that people had more capability or that their capability had increased. LP3 reported that sometimes she moved

past her calibrated maximum because she lived alone, and she had to no choice but to do certain movements despite the possibility of increasing pain.

LP3: “I have no choice sometimes. If I drop something, I have to bend to pick it up as I live alone but that does not mean that it is not a painful movement and during the day I may have a few of those. So it may show on there [the device], ‘look I did this today’, but may be you just had to do it because you dropped a glass of water on the floor and you had to bake. So you can’t always say, ‘I’ve managed to move a bit further today’”

To address this, some possibilities are to either automatically recognise pain or distress associated with the movement before considering recalibration or to detect outlier movements and remove them from the algorithm to recalibrate. However, another possibility is to treat calibration as a dialog between the device and the person where the device can make suggestions about recalibration, which can be tried and later accepted by the person. For example, this calibration could work as a suggestion of a percentage increase on self-calibration where the device can suggest that people try a small increase. Such a dialog can also be a measure to address situations where people may avoid increasing their range of activity for fear of increased pain or damage (discussed in Chapter 2, 7). If the device detects that the person has not recalibrated for a while even though their capability is improving (for example, by tracking fluidity of movement, lack of anxiety when doing movement), it can suggest a change in calibration. Conversely, if people move a lot and get regular flare-ups or tiredness due to overdoing (indicated by larger rest periods), the device can suggest a reduced calibration.

LP3 started associating certain sounds with pain, because when she was doing some tasks that pushed her past her limit, she felt pain and started associating the note that sounded at that point with pain. LP3 said,

“Although the app helps as a reminder to control movements more, it sometimes also makes me tense up more than I normally would. I think as the week goes on, I have started to associate some of the noises with a possible increase in pain and anticipating it makes me tense up.”

This points to a need for an automatic detection for the type of movement that is performed. For example, if the person calibrates a device for stretching forward but uses the feedback to do bending activities, they may find that the device feedback is not suitable. However, while using the device in a functional environment, it may not be practical to recalibrate every time a task is switched. One way for the device to do this is by storing calibrations for different movements and then switching the feedback based on the movement detected.

11.5.6 Overcoming social constraints

The participants described situations where they would like to reveal or conceal the device: in some situations with friends and family, they liked the fact that the device invited discussion. With knowledge of their social surroundings, they concealed or revealed the device dependent on the situation and their personal preferences. All participants used the device outside the home in different situations, such as on the bus or train (LP2, LP3), meeting friends at a shopping centre (LP4) and volunteering in a community kitchen (LP1). In situations such as on the bus or train, participants reported that they often maintained the same posture without moving or stretching because they felt embarrassed by drawing attention to themselves, or more conscious of their pain. In the volunteer kitchen, LP1 wanted to track and get feedback on her back movement in a busy environment where she was easily distracted. LP4 wore it to the shopping centre to monitor her movement and discuss the device with her friends as she often discussed her back pain with them. LP1 also used the device with a friend and her partner to discuss how her pain affected her movement and how the device could be helpful to her. We encountered three types of social uses that emerged from both studies with different needs, which are discussed here and summarised in Table 11-6:

Public use in the presence of strangers: Participants were not concerned about strangers noticing the device itself in public. LP4 said, *“Everyone’s busy, no one really notices”*. Further, they felt that the device was not obvious on the back and was easily concealed by light clothing if they wished. However, the sound feedback could draw attention to them and more importantly to their condition and cause embarrassment. So in some cases they used the device with the volume turned down. Participants felt that in public places it would be more useful to have the option of vibrotactile feedback. LP1 said, *“I don’t want to walk with my back pinging and turning heads”*. For most participants, headphones were not a viable option either. LP1, LP2 and LP4 felt that they preferred to be more mindful of their surroundings. Further, LP3 said, *“If I’m honest, I’d find the wave (continuous sound) feedback in my ear quite annoying after a while and overwhelming with everything else I have to be aware of when I’m outside.”* LP4 preferred to listen to her music if she was wearing headphones. For certain situations, participants felt that cued feedback would be useful to them rather than continuous sound feedback (e.g., a sound reminder to stretch on the train, to switch the backpack to a different shoulder - LP3).

Family and friends: Where there was likely to be more interaction with known people such as friends and family, people felt that sound feedback was too distracting and interfered with their conversation, so they stopped using the device in those situations or turned off the sounds. For

example, LP1 and LP4 used the device in situations when friends were present and switched off the sounds. People felt that the option to have vibrotactile feedback in these situations would be useful to them. While vibrotactile feedback had been provided with the device, people did not find it noticeable in busy situations, so it needed improvement.

Unfamiliar people: This category refers to acquaintances and as LP1 explained, *“people who I don’t know or barely know, not really friends but I may see them again. But again it’s also a familiar setting with people I may not necessarily know”*. LP1 was happy to wear the device in public but in the setting of the community kitchen, which was a boisterous social environment she found that she did not like people *“being curious and asking about the sounds and why I ‘need’ them but the way the sound feedback has been designed invites discussion.”* She felt forced to share information about her pain experience, which she considered private. However, even though LP1 switched off the sound she found the device useful as a reminder presence on her back to remind her about posture and stretching in a busy situation. Also in such situations, people started to tune out the sounds. LP1 said, *“if you think about it, it makes sense. We have an evolutionary reason to tune out certain sounds when we’re overwhelmed. Since this is a familiar sound now, I don’t hear it in that kind of [busy] situation or when I am focusing really hard [on something else].”*

All participants felt that it was important for them to have control over when to reveal (e.g. for LP3 as a way to talk about her back pain) or conceal (e.g. LP1 in the volunteer kitchen), which are examples of Goffman’s “protective practices” (Goffman 1959) during what he calls “impression management” onstage (Goffman 1959). While all participants felt that they would like to have feedback in these situations to pace their activity because they could be embarrassed (e.g., to change positions when sitting – LP3) or distracted/ immersed in the social interaction (e.g. when with friends – LP4). However, they felt the need for more feedback options based on whom they were with. For example, with unfamiliar people, they needed the feedback to be delivered through a different modality, either visual or vibrotactile because sound feedback especially continuous sound feedback was tuned out or too distracting. While vibrotactile feedback had been introduced with the device that was given for long-term use in the house, it was not strong enough to be felt through the layers of clothing and that part of the back is not sensitive enough to feel the vibration (Conrad-wall 2010). LP2 said, *“the vibrate function of the phone is really not strong enough to feel it very well. But you could wear it when you’re out and it’s not as intrusive as the noise sounds.”*

People felt that feedback related to pacing, reminders to change position and stretch could be very useful in social situations. However, it did not matter whether the feedback was from the

painful or tracked body part in these situations; they just needed it to catch their attention, such as “*lights on a wrist band*” (LP3).

Table 11-6: Social use of Go-with-the-flow device

Situation	Reaction to Sound feedback	Reaction to device	Suggestions
Public use	Tuned out/ Attention grabbing/ Embarrassing	Discreet under jacket (but study was conducted in autumn/winter)	Vibrotactile/ visual/cued sound feedback
Unfamiliar others	Distracting/ Embarrassing/ Tuned out	Not discreet enough	Vibrotactile/ visual/cued sound feedback
Friends/family	Distracting/ Interfering	Not discreet for formal settings but is not an issue in most situations.	Vibrotactile/ visual/cued sound feedback

11.6 Challenges faced by people in using the wearable device

Use of the device was hampered by the fact that people felt that it may fall off the back even though it was secured by Velcro or they wanted to use the device in positions where they were going to lie down and this was unfeasible or uncomfortable with the phone on the back. Also, many people grouped activities to perform together while using the device because they did not want to keep wearing and taking off the t-shirt with the device in it.

11.7 Discussion and Summary

Our studies in this chapter show how people adapt their homes and their own functional activities to better manage pain. We ran two home studies to investigate self-directed use of the *Go-with-the-flow* device in the home and presented the findings from our studies in this chapter.

The studies presented in this chapter aimed to explore the *Go-with-the-flow* framework and device for functional activity as previously it had been explored mainly for exercise (in Part 2). We wanted to explore functional activities because we knew from our initial studies with people with CP and physiotherapists that functional activities are used and even recommended. In running the home studies discussed in this chapter, it further emerged that exercise is strongly integrated with functional activity and that it is important for the device to be ubiquitous to support such integration. Indeed, we found in our studies, participants predominantly used the device to support function and incorporated exercise within functional activity rather than for typical exercise sessions in dedicated spaces. The scenarios that emerged showed the limitations

of traditional game-based approaches for home rehabilitation in CP and other conditions (e.g., (Jansen-Kosterink et al. 2013; Schönauer et al. 2011; Shin et al. 2014). In our studies, we found that people could be reluctant to use dedicated spaces for exercise due to restrictions such as space constraints, ambient light and temperature and other social uses of the space. Axelrod et al. (2009) also highlighted constraints of using home spaces for rehabilitation in stroke. In addition, one of the main reasons for integrating exercise into functional activity was the limited time people have to engage in exercise when physical and psychological resources are limited.

Our studies showed that technology has the potential to facilitate everyday functioning, not in an assistive capacity (i.e., compensating for limited physical capabilities (e.g., Farrell et al. 2007)), but as an enabling technology that provides the space to explore body capability. Further, exploration of body capability using sound feedback increased awareness of abilities and mainly provided the means to develop personal strategies to maximise the use of one's resources and to provide confidence in going beyond psychological limits when needed.

This is particularly important given that functional activity is the main source of physical activity in CP and because transferring physical gains from exercise to function is not straightforward. This is because while in exercise the person controls his/ her own targets and measures of progress, functional activity has predetermined targets because of the nature of the activity or the environment where the activity is to be performed (for e.g., there is a particular amount of bending required to load the washing machine). Most rehabilitation technologies aim to improve people's physical capabilities, but ignore the context where these capabilities will be used. One argument is that since a person can do a movement in a game, it should be possible to do it in the physical world. However, if the proprioceptive system is affected, as in CP (discussed in Chapter 2), it may not be able to give accurate information of capabilities (e.g., amount of bending), especially where emotional factors are involved. In addition, the person needs to work according to a pre-set target, which may be beyond their capability. This raises further emotional barriers to be addressed such as the need to improve confidence when transitioning from exercise to functioning especially in more cognitively demanding settings.

The *Go-with-the-flow* device gives a real-time representation of the body through sound. This can allow people to understand what the body can physically do because the activity is done in the real world and reinforced by feedback from technology. This feedback enhances the information given by the proprioceptive system and can make the body reappear to the person so that they can better judge their ability to accomplish activities. Technology in this way can help to represent the feedback given by physiotherapists in everyday activity, such as the behavioural experiments conducted during pain management education (discussed in Chapter

7). Technology can even go a step further by actively engaging and exploring possibilities in functional scenarios that are unpredictable rather than just allowing reflection on them.

The focus on self-directing activities also raised the need to identify strategies where possible to address the physical barriers. Within our studies we saw the emergence of clear patterns in the use of strategies for sonification to accomplish functional activities. But it was also clear that the motivation behind them was not always the same. It was also evident that people developed different strategies for their specific individual needs, psychological or physical capabilities or motivational triggers. While individual variability has been considered in technology design, it has mainly focused on providing motivation through tailoring exercises rather than facilitating functional activity (e.g., Balaam et al. 2010, Bagalkot et al. 2012). Here the variability is provided through the ability to use, exploit and operate the body when information is made available to do necessary functional tasks. So, the question is how to represent the body in a way that does not trigger emotional responses such as pain related fear when engaging in activity. Technology needs to provide a space for people to build strategies rather than embedding preconceived strategies into technology. The aim of doing so is to provide a means for people to explore and understand their body and capabilities. This challenges our thinking about physical rehabilitation where we just create space to exercise the body but do not provide opportunities for effective use of the body or its resources within contexts where people need to function.

Beyond personal factors, the variance in environments and roles of people within these environments needs to be considered when designing such technology. Our studies showed how technology can provide control by enabling the design of strategies to address physical limits in accomplishing necessary tasks (e.g., by helping to identify physical barriers in the environment and highlighting possibilities to adapt it to people's physical limitations or capabilities in a way that still encourages effort but within limits of capability). People also created strategies for using sound to fulfil different roles. The sounds were used in a (co) supervisory capacity in situations where people were anxious or distracted. The sounds could also play a companionable role to overcome social isolation.

In addition to self-directed strategies, what also emerged from our studies were clear opportunities for automatic adaptation of technology as it gains information about the person (e.g., environment, routine, capability). However, automatic adaptation by technology may not always be useful. In our participants, a lot of learning about one's own body and the development of strategies emerged from having to engage in calibration (Johnson et al. 2013) and explore capability. Hence it is important that a balance between automatic calibration and

self-calibration is maintained in technology especially when people are still developing self-management skills as this can help to maintain a sense of control over their rehabilitation progress. However, automatic detection of increased pain behaviour or increased confidence could facilitate co-discussion about calibration and possibly better learning of one's body movement and capability.

11.8 Limitations of home studies

These home studies are not without limitations. The study would have benefitted from lengthier interviews, additional observations, and more participants for better insights into use of the device and development of strategies. Furthermore, interviews could be demanding, time consuming and tiring for participants. Although we had a limited number of participants in both studies, the data we collected was rich, and provided both depth and breadth in terms of what barriers people face and how they use the device in their homes. However, in these studies, only recruiting women may have influenced the findings. We tried to recruit both male and female participants (see Chapter 4) as in our previous studies, but work and other demands forced our male recruits to drop out. Further studies with a more balanced distribution of genders are required to investigate the effect of the gender distribution on our results.

Chapter 12 A new Framework for designing Technology for physical Rehabilitation (RaFT)

From all our studies, it emerged that self-directed physical rehabilitation goes beyond dedicated physiotherapy-like sessions in the home and can take various forms. The studies discussed in this and the previous chapters have identified a set of factors that need to be addressed when designing technology for physical rehabilitation in CP beyond physical progress and motivation.

Unfortunately, there is a lack of models and frameworks to support the design of physical rehabilitation technology in the literature as discussed in Chapter 4. Hence, technology designers take inspiration from clinical-based physical rehabilitation approaches used in conditions where physical progress is the main target.

To address this gap, in this chapter, we use our findings and the literature to propose an initial framework for design of technology support for physical activity rehabilitation in CP. The aim of the framework is to guide designers through different considerations when approaching the design of technology for physical rehabilitation for CP outside the clinical context and away from the physical or virtual support of physiotherapists and clinicians. We will also argue, that some aspects of this framework may fit other conditions to a different extent based on the literature.

12.1 Rehabilitation framework for technology (RaFT)

Our proposed framework for designing rehabilitation technology (called RaFT) is an initial attempt to provide systematic support for the translation of needs and aims for physical activity rehabilitation into an implementable model for technology. Whilst the framework is mainly grounded on our studies in CP, we also consider findings from studies on physical rehabilitation in other conditions. Our aim is not to propose a framework that addresses all the requirements for physical rehabilitation in any condition, but to facilitate the analysis of the various personal (beyond physical progress) and environmental factors that play a role in physical rehabilitation. These factors are currently not considered in many physical rehabilitation technologies because they mainly replicate physiotherapy sessions outside the context of people's everyday lives. We have highlighted the psychological, personal, social, and environmental needs that interfere with physical activity in CP throughout the thesis. We do not argue that our framework encompasses

all the needs of other conditions, but we will discuss how they need to be addressed in other conditions and in doing so create a base for designing rehabilitation technology.

The RaFT framework is divided into two component parts: the rehabilitation needs component (Table 12-1) and the context and technology component (Table 12-3). These are discussed next.

12.1.1 The rehabilitation needs component (*henceforth referred to as P³*)

P³ highlights the fact that needs from rehabilitation are not just physical but also psychological. Further, rehabilitation needs to be integrated into people's everyday lives and thus there is a personal element that cannot be ignored when designing technology. **P³** thus includes physical, psychological and personal needs for rehabilitation and corresponding measures of progress for each of these needs for the specific condition that the framework is applied to; **P³** components are next presented in general a general form in Table 12-1.

Table 12-1: RaFT framework for physical rehabilitation technology: physical, psychological, & personal component

RAFT: P³			
LEVELS: P³	NEEDS		PROGRESS
1. Physical	Physical needs, capabilities, resources of the person: e.g. how constrained are the movements, how altered is the proprioceptive system, etc.	Interactions among P³ components and needs that cannot be easily separated due to strong dependencies / lack of independent measures.	The set of metrics that define progress towards goals over each of the P³ components.
2. Psychological	Emotional, cognitive, social resources and barriers to physical activity		
3. Personal	Personal aims, roles, goals (including social roles) to either recover (within what is feasible) and/or maintain despite limited resources.		

In the above table (Table 12-1), we present the general form of the framework to state the factors of the framework clearly. We will use this table here to discuss each component of the **P³** with reference to CP and extended to other conditions for rehabilitation based on the literature. At the end of this section, we will present the RAFT-CP framework for physical, psychological and personal components specific to CP in Table 12-2.

Physical

The physical component is the primary focus of existing rehabilitation technologies in the literature and includes physical aspects such as tracking and measuring movement. Preliminary

computational design models to address this aspect have been proposed (e.g., Egglestone et al. 2009). Increasingly, games-based approaches are being used, often correcting movement by exploiting *shift-of-attention* mechanisms to facilitate endurance during activity, and maximising performance by constant challenge (Holden 2005; Lewis & Rosie 2012). People need to be supported while doing physical activity, not only to maximise performance (such as number of repetitions, range of movement, pace of movement) but also to learn ways of using their bodies; for example, in CP, protective behaviours (e.g., moving stiffly, guarding, limping) (Aung et al. 2013; Sullivan 2008) associated with fear of further pain and damage due to activity, as discussed in Chapter 2. In CP, it is important to gain awareness of these physical behaviours, often habitual or automatic and to change them, since they are incompatible with physical goals such as increasing speed, power, and endurance as well as physical activity.

Psychological

Most rehabilitation technologies focus on improving physical condition of parts of the body or the overall body and act (directly) on the person to enable them to overcome physical barriers to movement, neglecting emotion. Even among the behaviour change frameworks in psychology (e.g., the behaviour change wheel by Michie et al. 2011) and persuasive technology frameworks (e.g., Oinas-Kukkonen 2012; Mohr et al. 2014; Fogg 2009), the role of emotion is restricted and primarily refers to the motivation to perform a behaviour. Our studies with people with CP in Chapter 7 indicate that psychological and emotional needs are equally important for physical rehabilitation as physical and personal needs. Psychological barriers in CP discussed in Chapter 7, exist in relation to performing movement (e.g., low worth of activity, fear, anxiety, worry, loss of confidence), in relation to accepting the limitations of their condition (e.g., anger, frustration, low mood), and in relation to social impact (e.g., embarrassment, feeling stigmatised, social isolation). Specific psychological needs for physical rehabilitation are also present in other conditions. For example, loss of confidence in stroke (Saunders et al. 2014), and fear of falls in Parkinson's disease (Jankovic 2008) and others and need to be addressed by rehabilitation technology designed for these conditions.

Personal

Technology needs to be designed to address people's real life interests and aims in addition to rehabilitation aims. Most technologies designed for rehabilitation do not focus on individual motivations for activity. Instead, approaches tend to focus on fun (e.g., Schönauer et al. 2011, Jansen-Kosterink et al. 2013), or exercise sessions in dedicated spaces (e.g., Tang et al., 2015). However, evidence is lacking for the potential of such systems to motivate people to self-manage their activity, particularly for functional improvement over time. Our studies suggest

taking a more personalised approach wherein people can work towards achieving personal functional aims and goals that are meaningful to them or towards reprising their social roles or developing new ones. Such a personalised approach has also been proposed in other studies of technology for chronic conditions (e.g., Zheng et al. 2010 for CP, stroke and congestive heart disease). Others such as Balaam et al (2011) also highlight a personalised approach in technology design for studies conducted in the homes of stroke survivors. However, their focus was on designing technology for particular situations that individuals enjoy to enable them to perform specific movements using those situations rather than facilitating functional activity which people need to do (e.g., pick up children from school, cook).

Beyond personal motivation for activity, technology needs to be personalised to the context of rehabilitation. Our studies have highlighted the importance of factors such as space available in people's homes, and attributes of the space in terms of light, temperature and social use by others in the home. People also prefer to do activity at certain times of day or within a routine. For example, some people do exercise in the bedroom before work, while others do it socially in the living room with their children. Such motivations need to be accounted for in the design of technology for rehabilitation in the home, differently from hospital or clinic.

Here, we present the instantiation of the RaFT-CP framework using factors that emerged in our studies and the literature in Table 12-2. In the next section, we present the second component of the framework.

Table 12-2: RaFT-CP framework for physical rehabilitation technology: physical, psychological, & personal component

RAFT-CP: P³			
P³	NEEDS & BARRIERS in CP		PROGRESS
Physical	<ul style="list-style-type: none"> • Limited/constrained /altered movement due to: <ul style="list-style-type: none"> ○ Pain ○ General prolonged inactivity or of specific part of body. ○ Limited or altered proprioception. • Central and peripheral sensitisation of pain system • Daily fluctuations in physical resources <p>Physical implications:</p> <ul style="list-style-type: none"> • Barriers to physical environments • Limited physical resources for everyday activity • Overdoing may lead to setbacks and increased pain • ... 	<p>Interaction between P³ factors (not easily separable).</p> <ul style="list-style-type: none"> • Where on the pain rehabilitation journey • Intensity and quality of pain • Dynamics of pain intensity • Behaviour, physiological, neural manifestation: 	<ul style="list-style-type: none"> • Improvement in amount (number of repetitions), range of movement, pace and quality of movement.

RAFT-CP: P ³			
P ³	NEEDS & BARRIERS in CP	PROGRESS	
Psychological	<div><div>Barriers/Reduce:<ul style="list-style-type: none">• Fear of pain and/ or damage, anxiety, anticipation of pain• Pessimism about activity• Low mood, depression, anger, frustration• Boredom, guilt• Low confidence• Pain coping and acceptance capabilities• Alienation of one’s body, embarrassment• Social isolation ...</div><div>Facilitators/ increase:<ul style="list-style-type: none">• Confidence• Sense of achievement• Sense of control• Motivation• Acceptance and re-engagement with one’s body ...</div></div>	<div><ul style="list-style-type: none">○ Avoidance/Protective behaviour○ Muscle tension & weakness (both involuntary and voluntary muscles)○ Altered respiration & cardiovascular function○ Altered brain patterns○• ...</div>	<div><ul style="list-style-type: none">• Better awareness of movement• Engagement in avoided or feared activity.• Increased confidence, reduced anxiety while doing movement• Recognition of cumulative achievement.• Ability to focus on pleasurable sensations• Remembering positive associations of activity• Applying self-management techniques, e.g., pacing</div>
Personal	<div><ul style="list-style-type: none">• Valued activities• Personal goals• Social roles with family and friends• Routines, constraints, activity preferences such as space, light, social context of the house.• Constraints of time and space• Preferences for source and types of feedback and support....</div>	<div><ul style="list-style-type: none">• Progress towards valued goals; re-engaging in social roles;• Ability to recognise and manage personal constraints and personal needs</div>	

12.1.2 The context and technology component (*henceforth referred to as W⁵*)

The context and technology component of the RaFT framework aims to systematically guide design of technology through focusing on design and implementation considerations for each aspect of rehabilitation technology. We organised the main factors that emerged from our studies into five categories that we call W⁵. The five identified factors are (i) **when** is an activity performed, (ii) **what** are the aims for rehabilitation (iii) **who** directs or supports activity (actors), (iv) **where** will the technology be used (context), and (v) **with whom?** In this section, we provide details of each of the questions (**Ws**). For each factor, a suggested context of application and the role of the P³ variables is presented to aid design of such technology. The constraints, roles and opportunities for technology for each level of the framework are also highlighted in the last column of Table 12-3. Parts of the framework can be used individually or tailored together to achieve different aims. After the table, we discuss each of the levels of the framework.

Table 12-3: RaFT framework for physical rehabilitation technology: context & technology component

RAFT: W ⁵			
LEVEL: W ⁵	CONTEXT	P ³	TECHNOLOGY: constraints, roles, opportunities
1. <i>When?</i>	During dedicated exercise sessions, functioning as a source of exercise (includes transferring skills from exercise to functional activity), and everyday functional activity.	How do P ³ barriers and resources change between the when of physical activities?	Should technology facilitate functional activity or exercise? When should technology track movements/exercises/functional activity and how?.
2. <i>What?</i>	What are the aims of physical rehabilitation: gain or maintain P ³ capabilities; build habits; build coaching skills; understand and trust body capabilities?	What P ³ components are targeted/operated on, and/or rewarded?	What component of P ³ should be monitored, regulated or enhanced? How can rehabilitation activity and feedback be calibrated or personalised to P ³ ?
3. <i>Who directs?</i>	Who (co-) directs or facilitates the different rehabilitation aims: e.g., self-directed, physiotherapist, close other?	Who should have access to the P ³ components	Does technology replace or support the Who? If it replaces the Who, what supervisory skills should it have? If it supports the Who, how can it facilitate application of coaching/management (setting goals, pacing, etc.)?
4. <i>Where?</i>	Where is the activity performed? This question aims to understand the environment and the level of control on it: e.g., a dedicated place or ubiquitous, adaptable (e.g. home) or not (public space)	How P ³ components affect (e.g., choice of place) or are affected (e.g., lack of control on environment) by the <i>where</i> . E.g., (organisation of the home; weather, time of the day)?	Should technology be ubiquitous or situated? How can it recognise the environment, be calibrated/ personalised to the environment and leverage/ communicate with the environment?
5. <i>With whom?</i>	With whom is activity performed? The aim is to identify the social context directly involved in the activity (not in a coaching role): e.g., exercising with family or friends, doing a task with a colleague, socialising with friends, riding a bus with strangers.	How P ³ components are affected (e.g., embarrassment, warmth) or can affect (e.g., create distrust or frustration in others) the “with whom”.	Should technology facilitate social inclusion: e.g., seek empathy and understanding by others and motivate (rather than just protect from) physical activity?

1. WHEN?

When designing technology for physical rehabilitation, an important question to be considered is “*When does physical rehabilitation take place?*” Our studies have shown that rehabilitation takes place in various contexts of a person’s life and that these are associated with specific needs. We have identified at least three main situations (i.e. types of activity) to design for: (i) typical dedicated exercise sessions, (ii) functioning as a source of exercise (includes transferring skills from exercise to function), and, (iii) everyday functional activity. Our studies have also shown that these *whens* could also be connected or even dependent on each other (e.g., doing an exercise can help to gain confidence in achieving a functional task). We briefly describe each of the *whens* here:

(i) Typical dedicated exercise sessions

Typical dedicated exercise sessions can be used to focus on increasing or maintaining physical capability. These sessions aim to recover or maintain physical capabilities, are generally done at fixed locations and focus on repetitive movements. This is the model used traditionally by rehabilitation technologies where people exercise in front of the television or Kinect (e.g., exergames for CP (Jansen-Kosterink et al. 2013), and exergames for stroke (Shin et al. 2014)). Some studies have pushed the concept of dedicated exercise sessions by incorporating them in social settings or linking them to enjoyable and valued activities (Balaam et al. 2011). However, the focus of these technologies is on motivation and engagement (e.g., Alankus et al. 2010; Balaam et al. 2011). In some cases, psychological needs are primarily met by the presence of the physiotherapist during rehabilitation (e.g., Doyle et al. 2010 for falls in the elderly; Jansen-Kosterink et al. 2013; Schönauer et al. 2011 for CP). In addition to the personal and psychological needs, physical needs of the condition under rehabilitation need to be taken into consideration. For example, in CP our physiotherapists focused on encouraging any movement and raising awareness of protective behaviour but in other conditions, such as stroke or rehabilitation following knee replacement surgery (Ayoade & Baillie, 2014), there may be much more emphasis on moving in a certain way. Technology also needs to aid development of habits of physical activity as discussed in Chapter 3 to generalise gains beyond exercise.

Function as a source of exercise (includes transferring skills from exercise to function)

People in our studies incorporated exercise/ stretches into their daily routines and practised them during functional tasks. They also used functional tasks as goals and to measure achievement and progress. For example, some participants in our studies put things higher up so they are forced to reach further to get to them. This embedding of rehabilitation in ubiquitous functional activity is also seen in other conditions (e.g., Bagalkot & Sodalaker 2011). In this

scenario, the context of functional activity is variable and technology has a mixed role of an exercise session but in an uncontrolled functional situation where there is no model movement to follow and where the space of execution is not predefined. It also means that movement may need to go beyond optimal targets set in exercise sessions as functional activity may demand that. It may further mean identification of strategies (either physical or environmental) to facilitate execution of movement. However, the aim is not just to compensate but also enable what the person can do. In this case, targets are defined by the activity and technology needs to take into account how the targets differ from the capability of the person and compensate or tailor feedback accordingly.

Transfer of gains between exercise and function is not typically addressed by technology based on traditional rehabilitation models. Transferring, when addressed, is limited to simulated real-life activities (Paraskevopoulos et al. 2014) in games or virtual reality environments, which ignore the complexities of mapping capabilities and extrapolating confidence from controlled exercise to everyday activity. Thus, while this approach appears effective in motivating and increasing physical performance in certain conditions, the simulated environment falls short in modelling the complex real world, especially when psychological factors are a barrier to function, making transferring very difficult. So it is also important to ask how technology can go beyond exercise and act as a bridge to function. Since transfer from exercise to everyday functioning is at the core of pain management this also includes identifying environmental barriers and addressing them through optimising physical and psychological resources. The use of wearable and ubiquitous technology, as in our study, shows how this biopsychosocial transfer can be facilitated not just physically but also psychologically. Technology can help to increase awareness of capabilities when people are doing a task and at the same time can help set targets from real world to exercise by identifying needs. For example, an exercise to reach up could transfer to an activity to reach for things (e.g., reaching for a plate while cooking). However, this same activity could be outside the home (e.g., reaching for a book in a bookshop). So technology needs to adapt to the context of the activity. Such needs for transferring function have been identified in other conditions. For example, in stroke, skills gained through rehabilitation exercise need to be transferred to daily function such as lifting a cup of tea to drink. So, to achieve functional recovery, movement training needs to be meaningful to the person and what s/he wants to achieve (Takeuchi & Izumi 2013).

Everyday functional activity

Whereas a strict separation between functioning as a source of exercise and transferring, and everyday functional activity is not possible, we separate them here to facilitate the design of

different technology based strategies. We differentiate between function as a source of activity and function itself in the sense that for the first time there is a clear focus on building capabilities. Hence, technology can be used to exploit functional tasks not just as a way to increase physical capabilities but also to increase the awareness and confidence in approaching the task itself. We envision that either a conscious shift of strategy by the person or some automatic detection may be needed to switch between the two.

In our home studies, people leveraged functional tasks as rehabilitative exercise. Beyond being able to function, facilitating ubiquitous activity in everyday life can boost confidence and address low mood by providing a sense of progress and control as discussed in Chapter 8 and some other studies in the literature (Duggan et al. 2015). Functional rehabilitation is important as often it is the only source of activity. For example, while loading a dishwasher, technology can enhance body and movement awareness through tracking and real-time or retrospective feedback to reflect people's progress towards goals during daily functioning. Further, the use of technology can be extended from just building physical capability to helping people to practise pain management principles described in Chapter 2, such as pacing (e.g., identifying when the person needs a break), relaxing (e.g., focus on breathing), stretching (e.g., when getting tense). In this sense, technology's role is supervisory as it can be used to give people reminders and raise awareness of their body during functional tasks where they may be focused on things other than their body. Technology can also augment pleasurable sensations and shift focus to aspects such as breathing in anxious situations or situations of high pain.

In Table 12-4 we present an example of using the RAFT framework to facilitate the identification of factors in unloading the dishwasher for the *When* level of the W^5 . Examples of different W^5 levels of the same activity are presented within discussions of the relevant level.

Table 12-4: RAFT-CP framework example for unloading the dishwasher, addressing the WHEN? Level of the W^5

RAFT-CP for unloading dishwasher: W^5: WHEN?		
CONTEXT	P^3	TECHNOLOGY: constraints, roles, opportunities
Unloading the dishwasher (situated context): - functional activity - provide	<i>Barriers:</i> <ul style="list-style-type: none"> • Anxiety about going beyond physical and emotional comfortable capabilities • Anxiety may motivate withdrawal or attempt to do as fast as possible • Low awareness of capabilities as attention mainly on anxieties or task • Protective behaviours may increase difficulty or pain of movement 	Technology needs to track the different movements involved: <ul style="list-style-type: none"> - Bending to first level of the dishwasher - Bending to lower level of the dishwasher - Removing contents - Weight carried -

CONTEXT	P ³	TECHNOLOGY: constraints, roles, opportunities
source of exercise: stretching, bending, carrying load, ..	<ul style="list-style-type: none"> • Attention to pain may block recall of plans and strategies (e.g., to unload dishes from lower level may need to kneel rather than bend) • 	<p>- May include walking to a different part of the kitchen to put things away</p> <p>Sensors: ubiquitous or fixed? Worn or not?</p>

2. WHAT?

Having identified ‘*when*’ physical rehabilitation will take place, the next question is, “*What are the aims of rehabilitation within that ‘when’?*” Since the ‘*when*’ is so tightly coupled with the ‘*what*’, we discussed aspects of it with the ‘*when*’. Each identified ‘*when*’ had a clear and different purpose, or a ‘*what*’. For example, within exercise the *what* might be to increase or maintain capability (see Table 12-3) and work towards achieving targets and goals. However, in functional activity the target for activity is not always so well defined and also psychological demand can change as sense of control decreases from exercise to function leading to more possible anxiety. While some targets based on exercise can be set within functional tasks, others may be dictated by the functional task itself. Technology can help by developing strategies for functional tasks where the demand is higher than a person’s capability. Function as a source of exercise can be a place to learn and practise strategies to achieve such tasks and keep track of progress towards functional targets. In everyday functional activity, technology can help with learning skills such as controlled breathing through a movement and better pacing. There is a synergy between exercise, functional activity as exercise and a means for transfer and functional activity itself, which can be leveraged by technology to achieve rehabilitation aims. For example, functional targets could further feed into dedicated exercise sessions for people to practise using feedback provided through technology to measure progress and reflect on how people achieve activity and pain management goals. Thus technology can assist with the transfer of skills from exercise to functional activity by setting goals for everyday activity, measuring progress towards that activity, and increasing awareness of movement so people are always aware of their body.

In Table 12-5, we continue the previous example of using the RAFT framework to facilitate the identification of factors in unloading the dishwasher. Here, we present the *What* level of the W⁵.

Table 12-5: RaFT-CP framework example for unloading the dishwasher, addressing the WHAT? Level of the W⁵

RaFT-CP for unloading dishwasher: W ⁵ : WHAT?		
CONTEXT	P ³	TECHNOLOGY: constraints, roles, opportunities
<ul style="list-style-type: none"> • Transfer of physical and emotional gains from bending, stretching, carrying exercises • Enhance awareness of capabilities while moving to increase self-efficacy and identify new capabilities. • Increase awareness of limitations when going beyond previous gains to remind use of facilitating strategies • Use of pain management skills such as pacing, breathing, breaks, 	<p>Physical</p> <ul style="list-style-type: none"> • Consider demands of whole day or remainder of day to decide on pacing strategy • ... <p>Psychological</p> <ul style="list-style-type: none"> • Monitor and regulate anxiety • Avoid exposure to movement when anxiety and fear is high • Enhance self-efficacy: facilitate application of gained physical and psychological capabilities and enhance awareness of them. • Strengthen ability to apply facilitating strategies • Remind use of pacing strategies if not applied (breathing, breaks) <p>Personal</p> <ul style="list-style-type: none"> • Understand personal preferences for extent and type of support 	<ul style="list-style-type: none"> • What types of sensors are needed - movement, physiological, etc.? What data needs to be fed back? What type of feedback is useful? • Calibrate technology to physical and emotional capabilities to provide real-time personalised support and increase awareness of capabilities. This could be based on both exercise and previous learning from performing the same activity. • Provide run-time feedback to <ul style="list-style-type: none"> ○ Enhance physical capabilities ○ Encourage and reward use of planned strategies especially when still learning to use them. • Detect protective behaviour that may lead to increased pain and increase anxiety; facilitate regulation (e.g., reminder about breathing, or changing position)

3. WHO?

Based on the ‘when’ and the ‘what’, described above, there are various possibilities for the ‘who’ component of the framework, such as: ‘who directs the rehabilitation? Who supports it?’ For example, in exercise, rehabilitation could be self-directed or directed by a physiotherapist/coach, supported by family and friends, or co-directed between two people who participate in the rehabilitation. People can also have different needs from the ‘who’ factor based on where they are in the journey and the demands they are facing.

In previous literature the roles of ‘who’ were achieved through activity tracking, rewards for activity and supervision to facilitate movement (e.g., Duggan et al. 2015) but did not focus on actuating functional activity. Assistive technologies (e.g., Farrell et al. 2007) attempt to compensate for absence of movement but do not focus on improving function. Rehabilitation technologies (e.g., Vogt et al. 2009) aim to increase awareness of body position during

rehabilitation exercises but do not address psychological barriers to regain control in everyday activity.

From our studies, two different roles for ‘*who*’ emerged for technology: (i) a (co-) supervisor to direct or share control (such as a physiotherapist, friend or partner. In this role the technology can provide reassurance, co-supervise use of resources, guide attention to important information for activity (e.g., being anxious) and even free cognitive resources when needed, and (ii) a self-representation that emerges through technology (e.g., through feedback to raise awareness) that allows the person to regain control of a body that had disappeared behind the pain as discussed in the findings of the home study previously. The representation is not just physical information: its design and calibration to the psychological needs and barriers allows the person to regain control and awareness of the body and movement. Further, this representation is within functional context and personal context allowing people to appraise their performance. This leads to confidence and the ability to develop strategies for self-directed functioning.

In Table 12-6 we continue the previous example of using the RAFT framework to facilitate the identification of factors in unloading the dishwasher by presenting the *Who* level of the *W*⁵.

Table 12-6: RaFT-CP framework example for unloading the dishwasher, addressing the *WHO* Level of the *W*⁵

RAFT-CP for unloading dishwasher: <i>W</i>⁵: <i>WHO</i>?		
CONTEXT	P³	TECHNOLOGY: constraints, roles, opportunities
Self-directed	<p>Should technology take a (co-)supervisory role?</p> <ul style="list-style-type: none"> What is the level of supervision skill already acquired? Is the user in a cognitively demanding situation where technology might need to provide support? What skills need to be developed/used? <ul style="list-style-type: none"> Being confident and aware of physical and emotional capabilities to self-management strategies such as setting targets and planning breaks for pacing. Attending to information from body related to movement and posture. 	<p>Provide a means for self-calibrating technology based on exploration of capability. Use feedback based on calibration to facilitate control over movement.</p> <p>Enhance awareness of capabilities and limitation to make use of the functional activity to transfer and build on capabilities when possible</p> <p>Enhance recognition of progress to set new targets in other activity</p> <p>.....</p>

4. WHERE?

The next important question deals with ‘*where is the activity performed?*’ Each context such as home or other public place has different characteristics and therefore requires a different type of support from technology. The aim of this question is to understand where rehabilitation is taking place as the level of control a person has on changing the environment for functioning can differ depending on if it is a private or public place. For example, the home can be adapted to the needs of activity but a public place cannot. In our studies people rearranged the home to make better use of their resources or to use functional activity as a source of exercise. Even in situations of greater control, such as within the home, our studies and other literature on stroke (e.g., Axelrod et al. 2009) revealed that rehabilitation may be affected by factors such as weather, light, temperature, time of day and social demands or space availability which need to be considered by technology designers.

Technology can also be used outside the home to remind people to stretch or to take breaks and pace themselves especially in situations of where people are busy or distracted by other things, beyond just providing motivation for increasing activity as in existing technology (e.g., Walky by Bagalkot et al. 2010). In Table 12-7, the RAFT framework example demonstrates the identification of factors in unloading the dishwasher at the *Where* level of the W⁵.

Table 12-7: RaFT-CP framework example for unloading the dishwasher, addressing the WHERE? Level of the W⁵

RAFT-CP for unloading dishwasher: W ⁵ : WHERE?		
CONTEXT	P ³	TECHNOLOGY: constraints, roles, opportunities
In the kitchen, it involves dishwasher, shelf, possible facilitating tools (e.g., chair, etc.).	<ul style="list-style-type: none"> Environment can be adapted to the need for exercise, such as by putting things further. <p><i>Barriers:</i></p> <ul style="list-style-type: none"> Shelf too high for capability leading to increased pain, Dishwasher lower level too low for extended bending activity <p><i>Opportunities</i></p> <ul style="list-style-type: none"> Use of chair to facilitate bending activity for longer period Doing stretches during breaks to reduce muscle tension and regulate anxiety Plan use of shelves (if possible) at levels that are reachable or just challenging. 	<ul style="list-style-type: none"> Beyond supporting the task of unloading the dishwasher (e.g., detect that the dishwasher is the task about to be addressed), technology could be used to facilitate re-arrangement of the room to facilitate use of gained skills. Building on these skills could be done by for example using the calibration and feedback setting to increase awareness of how the arrangement of the house facilitates it ...

5. WITH WHOM?

Rehabilitation (exercise) could also be in the presence of others, such as exercising outdoors, or swimming, which have their own set of variables that need to be taken into account by technology. However, when activity is performed socially, depending on who it is performed with, the psychological and personal variables may differ. Thus we introduced a level in the RaFT framework, ‘*with whom is the activity performed?*’ This could be the person doing the activity on his/her own, doing activity within a social context, such as doing an activity with friends/ family, other people with the same condition, or as part of a group of strangers. Various **P³** aspects affect this component, such as feelings of embarrassment or discomfort when with people who do not have an understanding of the person’s condition (Felipe et al. 2015), or positive emotions such as feeling encouraged by seeing others with the same condition do certain activities. Recently in exergaming literature, the use of balancing approaches (Gerling et al. 2014) is on the rise to enable people with varying skill levels to play together on a level field, thus providing enjoyable social experiences with potential for increasing physical activity and self-esteem through exergaming.

In addition to exercising with others, the ‘*with whom*’ aspect of the framework also includes social activities in people’s everyday lives. For example, in our studies with people with CP, they reported that while in social situations, they neglect to practise pain management skills; this is due to embarrassment or immersion in the situation. Rehabilitation technologies are designed to be used in situ and do not address such situations. Commercial technologies such as *Lumolift* (www.lumobodytech.com/lumo-lift/) or *iPosture* (www.iposture.com) can be useful for providing feedback for correcting back posture but they do not provide support for pacing activity or other physiological feedback such as breathing which could help to avoid overdoing activity or reduce anxiety and tension.

In Table 12-8, we continue the previous example of the RAFT framework to identify factors in unloading the dishwasher at the *with whom* level of the **W⁵**.

Table 12-8: RaFT-CP framework example for unloading the dishwasher, addressing the WITH WHOM? Level of the W⁵

RAFT-CP for unloading dishwasher: W⁵: WITH WHOM?		
CONTEXT	P³	TECHNOLOGY: constraints, roles, opportunities
<i>Alone</i>	<ul style="list-style-type: none"> Consider if technology should provide a more companionable role 	<ul style="list-style-type: none"> Technology can provide cues to remind of overdoing activity Reward and reminders of positive past experience can strengthen motivation.

12.2 Rethinking technology for CP

In this chapter, we presented a framework derived from our findings and the literature for the design and evaluation of rehabilitation technologies (RaFT). While our studies investigated needs in CP, some of our findings are relevant in other types of physical rehabilitation where people may face psychological barriers. Most of the technologies we reviewed are based largely on overcoming lack of motivation and do not address other psychological barriers. Also, as we discussed previously in Chapter 4, there is a lack of frameworks or architectures for the design of physical rehabilitation technology beyond computational ones. Assistive technology provides physical support but does not provide psychological support to improve functioning. Similarly to CP, in all these areas of rehabilitation, dedicated exercise is the most discussed aspect, whereas the emotional barriers to activity, especially everyday activity are ignored.

People with conditions other than CP for rehabilitation also need to transfer ability from exercise sessions to everyday function, such as picking up a cup of tea for a drink. In the P3 part of the framework, we presented how to address the psychological needs for rehabilitation in addition to the physical and personal. However, what changes for each specific rehabilitation condition is the instantiation of the framework, which is tailored to the condition. The use of such a framework is important to test and extend such technologies.

The RaFT-CP model is presented within each level of the framework above to illustrate its use in articulating the relationship between the types of activity, needs of users, rehabilitation aims, user types, technology-based mechanisms and context of use. This framework has a number of potential uses and implications for designing technology for physical rehabilitation support in people with CP. The RaFT framework can assist designers and developers of rehabilitation technology to formalise their intentions with respect to each design consideration, and to clarify implementation mechanisms that are important for achieving the aims of the technology.

In future research, experimental work will be needed to demonstrate the framework's applicability in various real-life design and usage situations for different rehabilitation conditions and contexts. The suggested framework, means for analysing the components and context for design may become especially useful in supporting and encouraging users to reach their own personal goals by overcoming barriers.

12.3 Limitations of the RaFT framework

There are several limitations and caveats to this framework. Most importantly, this is an initial proposal of a framework based on our findings but it needs to be validated. Next, the framework

is specifically based on CP and physical activity rehabilitation needs within it. While we expect it to be generalizable to other chronic conditions based on the literature, it has not been tested or instantiated for any other condition. Finally, the framework does not account for design processes, such as user-centred design. Design processes that integrate information on the needs, desires, and limitations of users into the development process are critical to ensuring that technologies are usable and useful and are needed in addition to frameworks such as RaFT.

Chapter 13 Ethics and empathy in encounters with people with CP

Parts of this chapter have been written as a position paper “Walk a mile in my shoes: reflecting on studies with people with chronic pain” and presented at the CHI workshop “Enabling Empathy in Health and Care: Design Methods and Challenges” at CHI 2014.

During the research presented in this thesis, we conducted many studies with people with CP in different contexts. These were embodied and situated encounters with people with CP and reporting only the words people said for the aims of research risks losing important details. We also want to highlight participants’ contribution and motives for participating in our research.

In this chapter, we have three aims: (i) to reflect on the role of empathy with participants and their condition in our HCI studies and thus enrich and contextualise the research; (ii) to illustrate with examples different encounters that were challenging for participants or for the researcher and how the researcher (and the research team) dealt with them; and (iii) to frame our reflections as insights for future HCI research projects that deal with such sensitive issues.

The rest of this chapter is structured as follows: we first discuss the need for empathy in conducting such research. We then highlight how we developed empathy skills through initial studies, including role-plays, interviews and focus groups. Next, we highlight different issues that emerged when evaluating the prototype with people with CP. We also conducted studies in the home and we discuss that context. We also reflect on the nature of dealing with some participants over time, such as developing familiarity and friendships. Finally, we present the impact of this research on the researcher. Throughout this chapter, we highlight insights gained and how they influenced subsequent studies or present them as learning to conduct such research. In doing so, we contribute to HCI an understanding of applying empathy in the context of sensitive research such as CP.

13.1 Enabling empathy

As we discussed in Chapter 2 and Chapter 7, CP is an invisible condition where often people encounter a lack of empathy because others cannot see what is ‘*wrong*’ with them. This can lead

to feelings that their condition is disregarded or minimised. Here, we reflect on the empathic aspect of some of our encounters when doing studies with people with CP.

To ground our reflections, we start with a definition of empathy. The online Oxford dictionary defines empathy as “*the ability to understand and share the feelings of another.*” There are three key attributes to empathy (Kouprie & Visser 2009): “(a) knowing what another is feeling, (b) feeling what another is feeling, and (c) responding compassionately to another person’s distress”. By using these attributes, empathic qualitative research allows the researcher a deeper grasp of how people make sense of their experiences and can help to engage with the user, gather reliable data and be a validating device when presenting the research (Watson 2009).

Empathy is important in HCI, to facilitate the understanding of people’s needs, values and emotions leading to better technology design (Wright & McCarthy 2008). It requires the researcher to immerse him/herself in the topic (barriers and enablers of physical activity in people with CP in this case). Researchers interpret findings by formulating them within their own social and experiential context. These experiences are grounded in the information provided by the participant but also inevitably influenced by the researcher undertaking the study. Researchers’ empathic emotional involvement and reactions to narratives of participants can help to build a trusting relationship, but also influence the interpretation of information they provide. At the same time, researchers can feel a gamut of emotion, from feeling worthwhile, to being frustrated on the behalf of participants’ when hearing their stories or feeling guilt at their own contribution to participants’ emotional distress (Moncur 2013).

In many HCI studies like ours, feelings and emotions are the direct focus of attention and what we aim to design for. In the case of physical rehabilitation for CP, fear of movement, further damage and pain are just some of the barriers discussed in Chapter 2 that technology aims to help to overcome. This means that empathy is at the core of our investigation. In the next section, we reflect on the role of empathy when studying the needs of people with CP.

13.2 Chronic pain: an invisible illness

People with CP may encounter a lack of empathy because others cannot see what is ‘wrong’ with them: they may not show any external or even internal signs of illness or disability. For example, one participant with CP related such an instance when, earlier that day, someone had joked about what she had done to get a disabled badge as there was ‘*nothing the matter with her*’. This illustrates what people with CP can encounter on a regular basis, leading to feelings that their condition is disregarded or minimised (Goubert et al. 2005) and they often feel stigmatised (Ashton-James et al. 2014), an experience that they may internalise (Waugh et al.

2014). People with CP can become socially withdrawn from friends and relatives and feel like a burden to them, may feel misunderstood by healthcare professionals (Cano & Williams 2010, , Nicholas & Blyth 2016) and in many cases are not able to get the help they need to manage their condition.

Against this backdrop, when talking to CP people about their experiences, it was important to communicate empathy to establish rapport. However, the researcher's '*empathic horizon*', (McDonagh-Philp & Denton 1999) was far removed from that of the participants, having no experience of CP. It was important to learn how to show empathy.

13.3 Developing empathy through consulting experts and conducting role-plays

Understanding the context of CP: Assuming an understanding of CP purely based on having experience of some pain can oversimplify the factors that affect a person with CP who may be living with pain for an extensive period of time leading to a long-term change of life. Knowledge of CP as a health condition, vulnerabilities and emotions developed through accounts in the literature, books and briefings from psychologists on our team helped the researcher to frame an initial empathic reference in this context, which was useful for designing further studies and dealing with people with CP. Role-play studies were designed to further identify practical situations that may not become apparent through the literature or discussion alone (Matthews et al. 2014); they helped to provide a "*realistic picture of what actually happens*" to "*see and hear how a person really operates rather than getting information through narration*" (Corsini 2010).

Communicating empathy, the use of language: Empathy plays a role in building trust and a rapport with potential study participants. We also learnt that language was important. For example, it was important to communicate that we regarded CP as a *real* disease. Further, language for questions and later discussions or even writing up was carefully chosen: e.g., words such as "*sufferer*" were not used in questions or presentation of the research as they can be depersonalising. Words convey unintended attitudes that can be hurtful to participants. But this kind of information can be elusive for HCI researchers so it was very helpful to obtain inputs of pain specialist psychologists and run studies such as the role-play with practitioners before starting field research and at regular intervals thereafter.

While we broadly specified patient roles and the setting for the role-play study, participants had the room to improvise as they were not given specific targets or goals. The dialogue and discussion during the role-play gave us insights not just into the process of a consultation, and

the kinds of issues that were dealt with by physiotherapists but also finer nuances of the interaction that helped with later studies and technology design. We observed the way that they asked questions non-judgementally, (*“Are there any particular stretches that have been bothering you?”*), expressing empathy to build rapport and trust and inviting people to share their views in a ‘safe’ environment, (*“I guess it must be quite scary if you don’t know what’s causing it [pain] and then I’ve given you some exercises, and you’re thinking ‘I’m not sure about these.’”*), summarising discussions to help with understanding and subsequent actions (*“it sounds like...”*, *“from what you say, we can agree...”*), and asking people about their beliefs (*“and what do you think could be causing that [pain exacerbation]?”*)

We also observed how physiotherapists maintained eye contact and neutral facial and vocal expressions even when the participant patient grimaced due to pain during an exercise. They were very aware of not dwelling on pain or painful expressions. If the role-played patient simulated pain during a movement, physiotherapists did not always respond to expressions of pain immediately but asked questions after the movement or gave suggestions to address it. Physiotherapists skilfully redirected the conversation back to physical activity and movement from other topics that might be brought up by the patients. These interactions were very helpful later to the researcher when she encountered similar situations, even though the researcher was not in a therapeutic role. It was helpful for the researcher to observe how physiotherapists redirected conversations from pain to activity and avoided tangential conversations. The researcher integrated some of these methods into her own approach for during interviews, focus groups and evaluations.

13.4 Developing empathy through interviews and focus groups with people with CP

The interview studies were the first of our direct studies conducted with people with CP, a step that is recommended by practitioners (Mattelmäki and Battarbee 2002, McDonagh-Philp and Bruseberg 2000, Fulton Suri 2003b). Talking to participants about their lives with CP is a sensitive topic that *“has the potential to cause physical, emotional or psychological distress to participants”* or to the researcher (Cowles 1988; Sieber & Stanley 1988). Conversations and discussions during the interview brought up issues or memories that were difficult and emotion-laden. At the same time, it was important for the researcher to stay focused on the question and to direct the interview without appearing to disregard the interviewee’s feelings. While we took cues from physiotherapists’ interactions and advice from the supervisory team (discussed in the previous section) which helped to manage interactions with people with CP during the

interviews, there were encounters we were not fully prepared for, or being there was not the same as role-playing it.

Affective state of people with CP: People often expressed frustration and anger in interviews about the things they had to do just to ‘maintain’ mobility, but they did not direct these emotions at the researcher. However, on one occasion, a study participant was in a low mood and displayed anger towards the researcher. Empathising with the affective state of the individual helped the researcher to stay calm, resolve the situation and remain positive. The researcher also directed the person to the information sheet to highlight that if anything in the study had caused her distress she should take it up with the principal investigator of the study. However, by then the participant was calm and explained she was upset because of a previous encounter on the tube where she was refused a seat, resulting in pain exacerbation due to prolonged standing.

Some participants enjoyed the opportunity to talk about their condition and often thanked the researcher for talking to them. Many seemed to discover insights into their experiences while participating in the study. Others felt that participating in research like ours validated that CP was a real problem in people’s lives and they wanted to participate in other studies. One participant said when leaving after the study, *“I feel it’s (CP) like real – it’s like validation. It’s difficult to explain to people about my pain. I will tell them I came to your study and then they will be interested because it’s science. So let me know if I can help again.”*

Communicating empathy, applying the right language: As we met more people with CP and gained more experience, it was easier and more natural to delve deeper into their words, derive a deeper empathic understanding of the condition and resolve implied meanings. The researcher obtained inputs of pain-specialist psychologists and physiotherapists at regular intervals to check terms used in study scripts and how appropriate they were. However, comfort with people and an improving understanding of the condition brought forth other aspects. For example, the researcher was challenged for saying, *“I understand”* by a participant who said *“you cannot understand what it felt like to wake up with pain every morning.”* This incident demonstrated the need to be careful of easy empathy, where researchers assume they understand the participant, and become complacent (e.g. through projecting our understanding on user accounts rather than being objective) and render the research unethical (Watson 2009).

Staying objective and focused: The focus of our studies was on physical activity experiences of people with CP. In the context of the emotional nature of learning about the impact of CP on their lives, it could be very challenging to adhere to the pre-set course of the interview. Some of the vulnerabilities that were shared made the researcher feel a bond to the participant, as they

were intimate aspects of the person's life. Some of the discussions brought up uncomfortable and painful memories for participants as well. To regain perspective, the studies were distributed over a longer time; the researcher also made time between conducting studies and doing analysis to reflect on practices (Johnson et al. 2012) and stay objective about the research.

13.5 Studies with a device

Based on the barriers, strategies and needs that emerged from our previous studies, (described in Chapter 7), we designed the “*Go-with-the-flow*” app (described in Chapter 8), which we needed to evaluate through controlled and qualitative studies with people with CP. During these evaluation studies, some new interactions and aspects emerged.

Wearing the device

When assisting people to try a wearable device, different issues came to the fore. The first issue was of design of technology: we knew that we would have to evaluate the device with many people for the control study, so we had to design some flexibility in the wearable solution to fit people of different sizes. Besides size of wearable, there were also issues with hygiene, as people would not want to wear a t-shirt that had been worn before by another. To address these issues, we designed a tabard that people could wear over their existing clothes, irrespective of size, with straps that could be tied under the arms. Since people might have limited mobility, in consultation with physiotherapists and the clinical psychologist on the supervisory team, we designed the tabard with no sides so people did not have to raise their arms to wear it and could slip over their heads. Our device also included respiration sensors which had straps that went around people's chest and upper abdomen; we made sure that straps were long enough for most people. These wearables are presented in Chapter 8.

Finally, the EMG sensors needed to be placed directly on people's skin on the neck and lower back to track muscle activity. This meant some people could be uncomfortable with the proximity of the researcher or allowing the researcher to place things on their skin under their clothes. We ensured that we asked permission to be in the person's space every time we needed to change something and to ask permission when we needed to touch them to adjust sensors – this was made part of the study protocol. We also always told them what we were about to do, especially when we were behind them, as with EMG sensors, “*I am now going to place the sensors on the back, is that ok? It may feel a bit cold*”. Researchers who did not need to be in the room to assist with wearing the device left the room to minimise embarrassment felt by participants. While other HCI studies also deal with putting sensors on people's bodies, an added concern in our case was that people could be in pain and adding sensors and other devices

on their body could lead to sensitivity or flare-ups. So, we needed to be mindful and ask them if they were concerned about the device in any way. For example, two of our participants reported that the feeling of the respiration straps made them feel confined and restricted and was painful, so we could not tighten the straps fully. Insights like this are an important consideration not just for design of wearable devices but also for studies where we ask participants to do things that can cause pain or discomfort. It also demonstrates an attempt to think of difficulties for patients that are not experienced with healthy participants, and builds trust.

While these are discussions that people who work in medicine or other disciplines may be trained to have, for HCI researchers inexperienced in dealing with patients they can lead to embarrassment for the researcher as well as the participant. In our case, we discussed the study protocol with a clinical psychologist experienced in dealing with people with CP and did test runs of the protocol with researchers who are used to dealing with patients to develop researcher confidence. The other problem with placing sensors is that it puts people in a more medical frame of mind and some asked if we could read and interpret EMG data for them. We were not ethically allowed to interpret this data for patients, nor was the researcher a specialist in doing so. It was helpful to reiterate while and after putting the sensors on that this was a computer science study and the researcher was a computer scientist not a physiotherapist or doctor.

Evaluating the device

During the control study, once people were wearing the device, the researcher asked them to reach forward with the device on the back. One of the participants found reaching forward very painful and slow while doing the study and she struggled to move back to neutral standing position from the stretch. However, when she was just having a conversation about something else, she did the movement freely without realising it. While the researcher noticed the movement, it was not possible to find a way of bringing it to the attention of the participant without the risk of causing offence. Clinicians are familiar with the fact that a movement made easily with distraction can cause difficulty and pain when it is the focus of clinician and patient attention, and often a cause of anxiety for the patient (see Chapter 7). Participants with sensitivity to feeling disbelieved might have felt “*caught out*” or undermined by the observation.

Participants were often inaccurate about their extent of movement, and although it was tempting to correct them from observation and readings from the device, we did not do so as this was not part of the study and we were not sure of the reaction we could get because of the sensitive nature of the issue. However, the question here is that would it be ethical to let the participant know that their movement was more than they thought it was. We did find when doing the

home study that such insights about movement were brought about just by using the device in everyday situations, while not being fully focused on the movement.

In some cases, people who came in for the study apologised to us if they were having a “good day” with low pain intensity as they thought this would be unhelpful for our research. Some offered to return another day when their pain levels were more intense. We had to convince them that our study would not be compromised because of their pain levels.

One of the participants did not hear the sounds when using the device because her movement was so small that the device angle did not change. She rated her perceived stretch as much higher though and we did not draw her attention to the sound. In another case, when the person stretched to the cupboard she was so anxious and focused on the movement that she did not hear the sounds that the device was making. When we asked her about the effect of the sound on her movement, she was very confused as she felt it was a “no-sound” condition.

Finally, in many cases participants were in pain or getting tired as the study went on. We offered that they should take a break or we could stop the study but many preferred to continue. We feel there is a nebulous line between protecting and patronising people but in our case, while we knew that people could have a flare up in pain if they overdid activity, we also knew that coming for the study was an effort for them and they wanted to make it count. Many said things like, “*I am not a quitter*”. While we took care in study design to ensure breaks were taken and study durations were not too long, people can have different capabilities that vary from day to day so it is difficult to plan for these situations. We always made sure that participants felt that they could make the trip back home by walking with them outside when they were leaving and we offered to hail taxis for them if they needed them.

Working with prototypes

There is another challenge of working with people who have real needs from technology but with early technology prototypes. For interaction/HCI designers a proof of technology concept needed to be tested and developed through iterative prototyping. In this case, the aim was to understand the potential, use and effect of the technology in different settings. However, there were things to consider. For example, technical issues such as the technology stopped collecting data and had to be restarted could cause people’s pain to get worse. Not only would people have a pain flare up later, their responses to technology might change if they were getting tired or their pain was increasing too much.

In such cases, we made sure to test the technology and prototype before each study participant arrived. Even then if technical problems occurred, we would ask the participant if they were

feeling well enough to go on. Even if people felt they could go on but we felt that they were getting fatigued we would move to different aspects of the exercise or in extreme cases stop the study. This was not an easy decision. It did not just mean that we would not collect data but also that the person often went away with a feeling of wasted effort.

Finally, there was the question of what we leave the participants with when we finish. We were not conducting a clinical trial but an exploratory study of using the device to manage physical activity, so participants' expectations needed to be very carefully managed. If we left the technology with the participants after completing the study, we needed to think of maintenance of prototypes when the project finished. However, removing the technology after saying that it may be helpful was also difficult.

13.6 Studies in the home

Qualitative researchers have highlighted the importance of location, especially when working with vulnerable participants (Dickson-Swift et al. 2008). Building rapport and empathy in people's own environments is easier than in other locations (Warr 2004). However, it introduces challenges such as conflict of role and relationship between researchers and participants, which we discuss in this section. When researchers enter participants' homes, roles can become blurred.

Role conflicts: social visitor, confidante and more: We were acutely aware that our presence in people's homes was significant and participants wanted to present their lifestyle in a positive light. Many people could be socially isolated and had few visitors so the visit of the researcher could be significant and novel. Some participants felt the need to tidy up and present their homes in the best light, but in some cases, they may not have had the opportunity to do so because of pain. In one case, a participant rescheduled twice and when we finally visited her, she told us that she was sorry about rescheduling as, "*it was a pigsty but I just couldn't face it (cleaning because of pain)*". When the researcher reassured her that she had a lovely house, she said, "*Oh, it didn't look like that before*". Thus, visits to the home are not effortless for participants. While people want to help with research, and may even enjoy the social interaction, they need to make an effort to let the researcher in and in some cases, have a stranger judging their homes. In other cases, people could be embarrassed about their space – one of the participants repeatedly apologised that her flat was so small and worried that we were uncomfortable because of it. Another participant who had children and pets had not been able to tidy up and she was apologetic about the mess but she said, "*I kept thinking they're coming and I must make the effort but in the end I just went to bed*".

Personal artefacts in the house could help the researcher to build rapport with the participant and give insights into the person and their interests, which could be helpful in conversations. For example, one of the participants had professional pictures of herself when she was younger in several prominent places in her house. When the researcher commented that she looked lovely in the photographs, she said that she wanted to think of herself as the person in the photographs, before the appearance of CP in her life, which had restricted her activities. She then described how pain held her back from some of the activities she had enjoyed when she was younger and how she would like to get back to doing some of them. This conversation seemed to make her more open and receptive to our study later.

The researcher also inadvertently got pulled into the role of a confidante with whom participants shared very personal details of their life (Russell 1999). On one home study visit the researcher was caught in the rain on the way to the participant's home. The participant kindly insisted on offering the researcher a cup of tea because she was going to have one herself. The setting was informal and relaxed as the participant and researcher made small talk. However, this informality led to the participant making disclosures about how her family had let her down after her father's death and one of her nephews had threatened her life last week, a matter already reported to the police. The researcher was unsure about how to react to this turn of events as the participant was obviously upset. HCI researchers working in sensitive settings may not always feel fully equipped to offer the support participants need (Massimi 2014) and this can be emotionally challenging for researchers (Moncur 2013) as discussed in the next section. To address the situation the researcher offered to finish making the tea while the participant took a minute. In doing so, the researcher had to become familiar with the home space and be the host. This highlights that with maintaining research boundaries in the home environment can be quite challenging as in such private spaces, participants might reveal more information than they would in other settings.

The incident (described above) stayed on the researcher's mind. The week after, the researcher received a text message from the participant (as she had agreed to participate in the diary study), that she would be dropping out as she had been assaulted by a neighbour. This was upsetting for the researcher who wanted to reach out but did not know what practical support could be offered within ethical constraints. The researcher responded to the text as she wanted to ensure that the person was being looked after (she was) and got advice from the psychologist on the supervisory team about if anything else could be done.

This situation was stressful for all involved and highlighted the need for self-care to avoid "*compassion fatigue*" (Figley 2002). In such situations, it is natural to empathise with

participants and express one's own concerns and experiences. Because of the emotional intensity, the importance of scheduling regular breaks to reflect, recover and prepare between studies became evident.

Timing the visits: We often conducted these studies at stressful times for participants. In one case, one of the participants was very stressed because she feared losing her welfare benefits at a forthcoming reassessment. She asked the researcher to look around her house saying, “*Does this look like luxury?*” Many other participants who evaluated our devices said, “*It looks great but I won't be able to afford it unless it's on the NHS or something. Can you do something like that?*” One participant told the researcher that he was not one of the “*rich kids*” with a smartphone but the technology might be more helpful to the next generation rather than “*old fogeys*” like himself. However, even though they felt that the technology might be inaccessible to them financially, people wanted to participate in the studies so that others benefitted from their insights about CP.

One of the participants was facing losing two family members at terminal stages of a disease. This was obviously a difficult time for her. We offered to call off the study but she said focusing on it helped her to get away from what was happening in her “*real life*”. However, during the study she found herself getting emotional about the current events in her life and we had to take a few breaks during the study for her to collect herself. While these visits had been organised at the convenience of people with CP, unforeseen situations made people more vulnerable at times. We had to empathise with their situation and give them options to continue or leave the research but if they opted to continue we had to focus on the research even though we knew they were feeling vulnerable. This also placed an emotional burden on the researcher discussed in a further section in this chapter.

13.7 Interactions with participants over time

In some cases, the researcher met participants many times during the research. Thus, being part of people's lives when they felt vulnerable, conducting studies in their homes, and seeing them as part of other studies that the researcher worked on (on CP but apart from this thesis), encouraged a bond with the researcher. The researcher also felt a connection with the participants because of knowing so much about their lives and empathising with them. However, it is the nature of qualitative research that the researcher controls the interactions and is more aware of the boundaries.

These boundaries were often blurred by participants. Many times, participants gave the researcher a hug when leaving. During some of the studies, the researcher was pregnant and a

couple of participants wanted to send gifts when the baby arrived. One of the participants wanted to knit for the researcher's baby and send her a parcel. There were other occasions when participants brought material unrelated to the study but related to an incidental conversation. Sometimes participants would email the researcher and offer to meet for a coffee or chat when they were near the University or send friends requests on Facebook, which the researcher could not accept. On some occasions, participants would update the researcher on how things had changed in their lives. For example, in one case, after two years of being interviewed a participant wrote to the researcher to say that he did not have CP anymore and would be visiting London soon, in case the researcher would like to meet and discuss this.

These vignettes highlight that researchers need to think about and be more aware of the boundaries of their research. However, there is also a need for a discussion of pragmatic ethical boundaries for research in a connected world of social media and easy access. The issues raised by people were personal to them and they naturally started forming a social relationship with the researcher.

13.8 Impact on researcher and researcher role

Undertaking emotion-laden and sensitive research can have benefits but also potential challenges and burdens for the researcher, which they need to be aware of and willing to work through. Interviews could be emotionally draining and at times forthcoming interviews were viewed with dread. Engaging in difficult emotional discussions with participants is not something that HCI researchers are typically trained to do (Moncur 2013). The researcher could feel out of her depth when engaging with such issues and was aware that she could cause real harm. For example, more than once, people interviewed expressed that they had felt like ending their lives in the past because they felt unable to cope with pain on a daily basis. In such cases, it was necessary for the researcher to think about an exit strategy to minimise distress and next steps (e.g. discussing with advisor). Further, constant reflection on the stories narrated by participants provided a good opportunity for immersing herself in the data but could cause deep emotional responses, causing a closer examination of the researcher's own life, both in terms of the positive and negative experiences. Support from the supervisory team (including a psychologist) and peers helped to cope and share the burden. In some cases, reflecting through note-making was also a coping strategy that helped with restoring personal balance of the researcher.

Beyond emotional wellbeing, researchers face other challenges, some of which are not restricted to sensitive solutions, such as managing conflict or more opinionated participants with quieter ones in a group setting. They also need to manage power equations within studies, such as

running focus groups with different stakeholders in our case. They may also need to stay calm and in control when faced with confrontation or conflict. For example, in one of the focus groups we ran, we asked participants what motivated them to do physical activity. One of the participants got visibly agitated by the question and said, “*Why do you (researchers and healthcare professionals) assume that we are not motivated?*” While she spoke on the subject longer, we were taken by surprise at the anger behind the question. At the time, we had to calm the situation and clarify our stance on the complete project, on how we considered CP to be a very real physical issue and also the meaning of motivation in our project as something to be addressed above and beyond the tackling of physical barriers associated with CP. We addressed not just the participant who raised the issue but also the others in the group.

By the time of this focus group, the researcher had previous confidence in dealing with such situations (e.g., many listed above) but there were some new researchers in the room who were clearly shaken by the confrontational tone of the participant. This confrontation could have derailed the whole focus group because it challenged the premise of the research and the authority of the researcher, professionally and in some senses, morally. While the researcher in this case had run enough studies to clarify where she stood on the issue in her own mind and hence handle the situation calmly, such situations can rankle and shake researchers’ confidence in running such studies due to lack of training and experience. In this situation, the researcher ran a short session after the focus group to debrief the other researchers and alleviate their concerns about such questions and situations. We also reported the incident to others on the project and the supervisory team even though there had been no negative outcome, to clarify the use of such words and also for future learning.

13.9 Discussion and Recommendations

HCI researchers, as a community, are increasingly reflecting on and gathering resources on the challenges of conducting research with sensitive populations or in sensitive settings through a growing number of workshops and special groups at CHI and other venues (e.g., Waycott et al. 2015a, Branham et al., 2014). In this chapter, we have contributed to this ongoing discourse in HCI by presenting situations that emerged in our studies and by reflecting on our actions at the time of the incidents (e.g., how we addressed them or how they shaped further studies). In presenting these situations, one of our aims was to contextualise our studies and the position of the researcher to provide an improved understanding of our methods and results as these factors influence data collection and analysis. However, and equally important, we also presented ways of addressing some of the issues that arose that can be used by the wider HCI community. We do not present these reflections as solutions but open them to debate about what are the best

ways to deal with such issues. This can be especially helpful for researchers new to conducting research in sensitive settings. We do not always present solutions, because in many cases there are no wrong or right ways of approaching such situations. However, we do present the realities of doing research such as this where there is risk to participants and researchers if we do not learn from past experience or find ways to build on them in the HCI community.

We outline here three key points that emerged from conducting our studies. While such sensitive cases have been discussed in recent HCI literature (Waycott et al., 2015b), what we aim to do in this section is to present practical strategies that we adopted to build on our experience of these studies. The key points are: learning to apply empathy in unanticipated situations, power sharing with participants, and self-empathy and developing researcher support strategies.

We do not intend this as a comprehensive list of issues or strategies but as a means to start the process of taking concrete steps to enable empathy in sensitive HCI research to be conducted with preparation and thought to issues beyond the semantics of the study itself. These recommendations aim to benefit both researchers and participants. In doing so, we are contributing to improved practices for conducting HCI work in such contexts.

13.9.1 Learning to apply empathy in unanticipated situations

Unanticipated situations: While the process of applying for ethics tries to anticipate some of the concerns (or tries to), a lack of experience of conducting sensitive research, especially in the case of HCI researchers, means that these issues may not be adequately thought about or addressed at that stage. Some issues cannot be anticipated unless a researcher has been in a similar situation. While strategies such as the development of an *empathic horizon* for the problem, careful planning of the study and access to experts can help to anticipate a lot of issues that may arise during studies, we acknowledge that new ethical dilemmas are inevitable in such research and all situations cannot be planned for. Such unanticipated situations require quick and sure responses from the researcher, giving weight to the concept of “*situational ethics*” (Munteanu et al., 2015). While we agree that situational ethics need to be better integrated with formal anticipatory review processes (in agreement with Munteanu et al., 2015, Waycott et al. 2015a), we recommend training to ensure that HCI researchers are prepared for some of the situations that may arise or know how to deal with the aftermath of such situations.

Sharing experiences and increasing exposure: To do so, we recommend that researchers who gain some experience with the relevant population should conduct role-plays based on their evolving understanding from experts and participants. Real issues and languages can be role-

played based on personas created by the experienced researchers. While such role-plays are commonly used for sensitising designers to creating new technologies, we recommend doing them with researchers to go out into the field. Even experienced researchers can get new insights when participating in such role-play situations. For example, in our project, the researcher learnt about how to communicate empathy and establish rapport from observing group sessions in hospitals, physiotherapists in role-plays and being exposed to different situations in the studies. However, all researchers do not get such exposure due to shorter projects and long waiting times to get ethical approval for research in such diverse settings. Besides, clinicians have limited availability. Hence to prepare other researchers on smaller projects or doing MSc dissertation projects, the researcher felt equipped to run role-plays them to prepare them for research with participants who had CP. This helped researchers to feel more prepared for studies with participants with CP and we could minimise the risk of causing offence through insensitivity and inadequate preparation. This was also a preparation to deal with situations that could arise if participants felt vulnerable or in a negative emotional state. Further, this helped the experienced researchers to rehearse situations and learn new ways of dealing with them, so it was not only for the benefit of new researchers.

13.9.2 Power sharing between participant and researcher

The use of labels: Studies such as ours can expose participants to distress and feelings of being disempowered, misrepresented or misunderstood (Waycott et al. 2015b). Labels that we use to describe participants such as “vulnerable” (Vines et al. 2014) or “sufferers” can also disempower them. We need to be mindful at every stage of designing studies as well as designing technologies of the language that we use.

Balancing power: Increasingly participants are co-designers and co-researchers in our projects but we need to ensure that power equations within studies also support this. For example, when we designed a focus group with physiotherapists and people with CP, we tried to ensure that the people in the focus group would not feel intimidated by the presence of healthcare professionals. Such planning can help participants as well to gain more from the process of being involved in our studies.

Balancing current situations with the greater good: Inevitably with the design of our technology, to make things that support a future goal such as increased physical activity in people with CP, we can expose vulnerabilities in study participants. In some cases this is because the technology is at an earlier stage than the finished product, or we do not understand enough about how people will react to a technology until the first studies of it. For example, when running the control studies of our wearable device, the breathing sounds made some

people anxious. While such reactions informed our design and future prototypes will address the issue, at the time we need to address participants with empathy and have a protocol in place to deal with participants. For example, in the case of the breathing sensor, we asked participants if they felt able to continue, offered them a break and refreshments and explained our reasoning for the design. We also set up expectations from the outset: such as this was a prototype not a final product and we were designing technology to support physical activity and it would not cure or improve their pain. We also needed to ensure that participants were always aware that we were computer scientists not healthcare professionals.

Respecting participants times and resources: In our case, participants could have problems with coming to the venue or inviting us to their homes. As a research community, we suggest that where possible we should always offer the possibility to use phone or online mediums for study or organise studies at venues convenient to where the participants may already be need to go. This can minimise disruption to participants and increase participation in our research. Even in studies in the home, it may be important to be mindful of the effort participants may need to make to invite researchers and always question ourselves about whether making the visit is crucial to the study or the exchange could be done in a more convenient way for the participant. Again, it is possible that participants prefer personal contact but these are decisions that researchers can make depending on their interactions with participants.

Power with the participant: There can be situations where the power dynamic is changed and the researcher feels disempowered with respect to the participant owing to the situation or reaction of the participant. For example, if a participant is rude to a researcher. While empathy plays a role in dealing with these situations, researchers should also develop strategies for how to stop and exit from these situations.

13.9.3 Self-empathy and investing in researcher support strategies

The focus on researcher wellbeing in studies such as this has been increasing (e.g. Moncur 2013). In addition to those strategies, we propose that researchers need to focus on building their own strategies for such research, within their study protocols and plans. In fact, in case of researchers inexperienced in such types of sensitive research, guidelines should be include strategies such as building time into study plans for taking breaks from data collection and analysis for active self-care, debriefing with others on the team especially in ethically-charged projects and writing reflexive memos during their research. Also, as others have suggested, there should be support on the supervisory team or project team for such projects where an expert can be present to address issues and answer questions (Waycott et al. 2015b, Vines et al. 2014, Moncur 2013).

Some of the questions, when participants are distressed, that repeatedly occurred to the researcher when working on this thesis are, “*Was it me (that caused distress) or something in the person’s life? Could I have done something to avoid it? Could I have done something to alleviate it? Was the person ok afterwards?*” Having someone available to answer these questions is important to researcher wellbeing especially if the person knows the researcher and the project. Such support was available in our case and we recommend its use. In many cases, we found that such support is available within universities if not in the department, but researchers are not always aware of this or such support is not made obviously accessible. A set of guidelines on projects such as this on who to speak to after running these studies should be made part of the project study protocols. Also, it may be helpful if senior researchers on teams are proactive in questioning researchers about recent studies or share their own experiences in doing such research.

However, in practise, senior researchers may be busy, project deadlines may be tight and researcher wellbeing may take a backseat. We suggest that researchers should practise self-empathy and this should be emphasised when designing studies within teams. Actively seeking help and opportunities to discuss research experiences can help researchers think about them more objectively. We aim to create an online group of research experiences for sensitive research in HCI that can act as a depository of experiences and blogs on this subject but also help researchers find others who have worked with similar populations to exchange ideas, not just on empathy and ethics but also recruitment strategies and other issues.

13.10 Conclusions

Empathy is vital to the qualitative researcher to develop a rapport with the user. However, empathy in HCI needs more definition and frameworks like (Kouprie & Visser 2009) but with more support for the researcher and for research involving vulnerable populations. As researchers, we need to balance empathy by applying scientific rigour to our attitudes, challenging assumptions and ensuring that we are not patronising, stereotyping or biasing our participants or research through our words or approach. More discussions like this in the HCI community can help create guidelines and regulate such research.

Sharing research experiences like we have done above means that researchers are more open to criticism and their methods and reactions more open to question. In some cases, researchers need to expose their own vulnerabilities in presenting these cases. However, it is important for this reflexivity to improve the design of our research, our interactions with participants and ultimately to take care of our researcher selves.

Chapter 14 Conclusions

The work presented in this thesis addressed the research question,

How can interactive technology support people with CP in overcoming psychological barriers during self-directed physical rehabilitation?

We divided this question into three sub questions that were addressed through a set of incremental studies:

*RQ1: **Understanding:** What are the barriers to physical activity faced by people with chronic pain and what strategies are used to overcome them?*

*RQ2: **Empowering:** How can sensing and feedback technology be used to address barriers and implement/ extend the identified strategies?*

*RQ3. **Functioning:** How can interactive real-time feedback facilitate (i) self-directed physical activity in the home (including functional activity), and (ii) enable transfer of gains from exercise to everyday functional activity?*

To address the research questions proposed for this thesis, we conducted various qualitative studies with people with CP and physiotherapists, reported in Part 1 (Chapters 6-8) of this thesis. Based on our findings from the qualitative studies and using an iterative design approach, we developed a sonification framework and instantiated it through a wearable device, reported in Chapter 9, called *Go-with-the-flow*. The aim was to provide real-time sound feedback tailored to psychological needs and physical capabilities to enhance body and movement awareness and rebuild confidence in physical activity. We conducted several studies to investigate the use of the framework in self-directed rehabilitation. We also conducted home studies to understand how the *Go-with-the-flow* framework and device could facilitate unsupervised self-directed physical activity in the everyday lives of people with CP.

14.1 Contributions

This thesis is fundamentally concerned with and contributes to the fields of human-computer interaction (HCI), technology for behaviour change and rehabilitation technologies. By proposing a novel sonification framework to address psychological and physical needs of people with CP, this thesis contributes to the HCI and rehabilitation technologies literature. It contributes to the field of behaviour change by bringing emotions (beyond motivation) to the centre of design of technology for behavioural changes. By proposing the RaFT framework for

CP and generalising it as a first step for other conditions where psychological factors are critical to rehabilitation, we contribute further to rehabilitation technology literature. This thesis also informs affective computing literature with situations where people need support based on automatic recognition of affective state or movement behaviour.

In particular, this thesis made five main contributions.

14.1.1 Contribution 1: An in-depth understanding of barriers to physical activity in people with CP and strategies to overcome them

In the qualitative studies we reported in Part 1, a rich picture of the affective barriers to physical activity in people with CP emerged such as pessimism about activity due to high cost of pain, fear and anxiety, low mood, and social isolation and how each of them interferes with physical activity. In addition to the barriers, what also emerged from our studies, were the strategies used by people with CP and physiotherapists to overcome those barriers. We found that while motivation through reinforcement and reward was important, physiotherapists went beyond this to address affective barriers. They focused on making people rediscover their body and its capabilities and limits through exploration and worked with people with CP on gradual (re) building of physical and psychological capabilities. At each stage, they focused on building awareness within people so that they could self-manage their activity rather than being dependent on physiotherapists. Strategies were not only based on physical progress but also psychological progress and development of self-management skills. Further, the focus was not only on doing exercise but also on self-managing functional activity and taking responsibility for progress as in other chronic illness (Mynatt et al. 2010).

These findings were in contrast to existing technologies to support rehabilitation and physical activity reviewed in Chapter 4 that mainly focused on motivation through tracking activity and rewards and physical progress. Emotional support beyond motivation was not considered and possibly individually addressed by the presence of physiotherapists during the studies, based on other models of rehabilitation such as stroke (Schönauer et al. 2011). Even in the behaviour change literature reviewed in Chapter 3, most behaviour change theories focused on forming intentions and motivation as the basis for changing behaviour, not on affective barriers that held people back from performing behaviours. While tracking activity and rewards are useful, our results showed that people may not feel capable of the behaviour and addressing affective barriers in CP is important to encourage people to do activity.

An in-depth analysis of these barriers and strategies that emerged from our study, led not just to a better understanding of needs required for technology but recognising that we needed to

rethink the role of technology to be ubiquitous (unlike situated game-based approaches), functional (not restricted to exercise) and adaptable to account for variable progress. This rethinking of technology led to our next contribution.

14.1.2 Contribution 2: A psychologically driven sonification framework to facilitate self-management of physical activity (*Go-with-the-flow*)

In Part 2 of this thesis, we proposed a sonification framework called *Go-with-the-flow* to support the design of sonified exercise spaces (SESSs) for people with CP in doing physical activity by empowering strategies that address psychological and physical factors identified by the studies presented in Part 1. Our framework's novelty is in our approach of tailoring feedback for psychological capabilities (i.e., what the person feels she or he can perform), unlike other traditional physical rehabilitation and motor learning applications which focus only on physical capability (Hermann & Zehe 2011; Schaffert et al. 2010). In our framework, sonification was used to provide an external representation of movement for enhancing awareness of body movement and position in real-time. For tailoring sonification, we used anchor points to define the sonified exercise spaces (SESSs) that targeted psychological capabilities and provided information about movement. The shape of the sonification was designed to provide a sense of achievement.

Our SESSs were designed to build confidence in movement and to reduce anxiety rather than for rapid increase in physical performance (Vogt et al., 2009) or signalling goal achievement (e.g., Wallis et al., 2007). Through self-calibrating the device to their own movement people were able to tailor their own strategies for movement in different contexts.

We also used sonification alterations to make people aware of protective or altered body movement and also to signal preparatory movements within more complex movements. Unlike other applications in stroke (Rosati et al. 2013) or balance rehabilitation in elderly people (Paraskevopoulos et al., 2014), our framework was used to increase awareness and a sense of control. Our wearable device demonstrated the possibility of skills transfer from exercise to functional movements through calibration of the device to everyday functional activities.

We also explored breathing to address anxiety during physical activity using breathing sensors for signalling shallow breathing or holding breath, which can potentially affect ease of movement due to anxiety (Perri & Halford, 2004). While people found the concept useful, there were issues with the way we had designed the breathing that could provoke anxiety as discussed in Chapter 10. This and other extensions are being explored in a further PhD project (Newbold

et al. 2015) that is building on this work. Our sonification framework is also being explored within the Ubihealth network for applications in engaging children with autism.

In making the sonification framework and wearable device, the potential of the device in facilitating everyday functional activities became more pronounced and led to the next contribution.

14.1.3 Contribution 3: Using sensing technology to facilitate functional activity in the home.

In Part 3, we investigated the use of the *Go-with-the-flow* framework and device to self-manage functional activities in the home, beyond exercise. Our studies showed that using the device increased awareness of body and movement capabilities during functional activity and exercise. People used the self-calibration function to gain a better understanding of their body and capabilities in different contexts including different social contexts. This awareness and understanding provided them with tools to develop strategies that they could use to function more efficiently by tailoring strategies to achieve their personal goals, needs, capabilities and motivations. In addition to physical and psychological capability the device was also used to help with pacing activities in the home. Another aspect of our device that was used by people was transferring strategies used in exercise to function and vice versa, a function that is largely ignored by rehabilitation technologies as discussed in Chapter 11.

People were also able to adapt their environment in an effective way to support them in functioning better and to allow for gradually building of psychological and physical capabilities in functional activity. While some other technologies have recently emerged to support functional activity in the home for people with CP (Duggan et al. 2015), they focus mainly on activity tracking and motivation. Others (Balaam et al. 2010; Bagalkot & Sodalaker 2011) focus on integrating technology in the home to motivate exercise routines, not to facilitate functional activity. This is unlike our approach, which focuses on facilitating functional activity within the home.

14.1.4 Contribution 4: A framework for designing technology for physical rehabilitation (RaFT).

During our research in this thesis, we encountered a lack of frameworks for designing physical rehabilitation technologies beyond computational models or frameworks that focus purely on physical capability as discussed in Chapter 4. This lack of frameworks led to an initial proposal of the RaFT framework based on all our findings in Parts 1, 2 and 3 of this thesis and the literature. The RaFT framework includes factors that technology designers need to consider to

address people's physical rehabilitation needs in CP. The framework focuses on the interaction between the physical, psychological and personal needs that technology must address with the type of activity, where it is executed/ performed, who directs it, who participates in it, what are the rehabilitation aims and how can technology be used to achieve the goals of activity. While the framework was developed based on the needs of people with CP, we argue that it can be generalised to other conditions based on the literature (e.g., stroke) but this needs investigation.

Through this contribution and the way we approached it, our aim was to move emotion to the center of physical rehabilitation, beyond motivation that is the target of rehabilitation technology. Through the framework we also target other factors such as personal, social and psychological in addition to physical factors for rehabilitation. The RaFT framework's contribution is that it provides a structure for designers to identify factors that need to be considered to support physical rehabilitation in people with CP (and potentially other conditions).

14.1.5 Contribution 5: A contribution on the role of empathy in designing and conducting studies

A final contribution of this thesis is a reflection on our studies on ethical dilemmas and the role of empathy. We presented in Chapter 13, how empathy was developed in a new context unfamiliar to the researcher, how it was important for interacting with participants with an *invisible* illness (CP), and for designing studies. Through these reflections we focus on the impact of studies such as ours on participants and the dilemmas that face researchers during and after these interactions. We also focus on the emotional impact of such research on the researcher. These reflections are important as research such as that presented in this thesis is not conducted in a vacuum but is profoundly affected by the researcher's values and in the context of the research. Locating the researcher's position within these studies is becoming an increasing focus in HCI. We also make several practical recommendations for HCI researchers that we used in running our studies. This contribution can be useful in developing new training programmes or new initiatives to support researchers.

14.2 Practical implications

Besides contributions to the scientific literature, the work presented in this thesis also has implications for the design of sonification and wearable technologies for people with CP as well as other rehabilitation discussed in Chapter 9.

14.3 Potential directions for future work

The research in this thesis was focused on designing technology for people with CP to do self-managed physical rehabilitation. We applied the findings to a rethinking of technology in CP rehabilitation and proposed a sonification framework to provide real-time feedback during activity and a RaFT framework to design technologies for rehabilitation. The work in this thesis has paved the way for four broad areas of further research. Each of these avenues would be interesting to pursue.

The first area is the extension of the sonification framework (*Go-with-the-flow*) in six aspects: (i) to sonify multiple body parts, (ii) to multiple feedback modalities, (iii) to focus on the maintenance part of the journey, (iv) to transfer confidence gained from exercise to functional activity and extend this confidence to contexts of high cognitive/ emotional demand, and (v) to facilitate sharing strategies to build capabilities, recognise progress and support others, and (vi) in other exercises beyond reaching and bending. The second area is that both the frameworks proposed (*Go-with-the-flow* and RaFT) could be applicable beyond the scope of CP rehabilitation.

14.3.1 Extending the *Go-with-the-flow* sonification framework

We developed the sonification framework, described in Chapter 8, to support self-directed physical activity in people with CP. Many directions for extending the framework emerged from our studies and we discuss them here.

Area 1: Extending to multiple sensors sonification to engage more parts of the body

Presently the framework for sonification has been evaluated only for one sensor associated with a particular part of the body at a time providing feedback for movement for that part. The only exception was when multiple feedback was made available to people for breathing and movement as discussed in Chapter 8. The framework can potentially be extended to tracking and giving feedback for multiple parts of the body. Further, the design of the device can be made smaller and small sensors can be used to track the body with centralised integrated feedback through the smartphone or another device.

It is important to extend the use of tracking and feedback to multiple parts as people with CP may ‘guard’ body parts they feel are at risk and overuse others as discussed in Chapter 2. Anxiety or focus on pain can also affect breathing patterns. Thus, an investigation of how the *Go-with-the-flow* device can increase awareness and engagement of different body parts and breathing particularly during functional activity will be useful to designing a more holistic technology for everyday support.

Area 2: Extending feedback modality

This thesis also focused only on real-time sound and vibrotactile feedback to a limited degree. Therefore, the aspects of the *Go-with-the-flow* framework only currently apply to sound and to vibrotactile feedback in a very small way. While many of the factors could still apply in the case of feedback in another modality but others are modality specific. Further research needs to be carried out to make the framework and the guidelines truly multimodal.

In our studies some contexts emerged where participants were unable to use sound feedback. In those situations, especially, some of them felt that wearables that gave visual feedback (such as a bracelet that lights up) could be useful to them.

Area 3: Focusing on the maintenance part of the journey

The sonification framework increases awareness of the body based on people's own needs and capabilities. It is a ubiquitous framework that can be applied to many everyday contexts especially in situations where cognitive load is high. Through the framework, we shifted the focus to psychological factors affecting activity in CP as these are underrepresented in rehabilitation technology. However, we focused only on the exploratory and to a small extent the building of activity in the pain management journey. We believe that the frameworks can be extended to maintenance of activity but this was not tested by us.

Area 4: Transfer of confidence from exercise to functional activity and extending this confidence to contexts of high cognitive/ emotional demand

Our participants appropriated the wearable *Go-with-the-flow* device to try to design personalised sonified movement strategies (SMSs) that integrated comfortable sonified exercise space (SES) boundaries with functional targets, transferring skills from exercise to everyday activities (e.g., cleaning, shopping) as presented in Chapter 8. In doing so, they highlighted the differences between SESs and SMSs and further psychological needs for functioning. There is a need for further investigation and evaluation of feedback strategies for building confidence in exercise (SESs) and how such feedback strategies should be adapted during functioning (i.e. SESs → SMSs) so that feedback about preparatory or intermediate movements is included to facilitate the target movement (e.g. positioning the feet and bending the trunk forward before standing up from a seat that is lower than the one chosen for training; or turning to face a shelf to reach for a book rather than twisting the trunk). In addition, functional activity may require going beyond pre-set training boundaries (e.g. a shelf in a shop may be slightly higher than one in the re-organised home to fit CP). This may require additional feedback to indicate going beyond boundaries and knowing if beyond is acceptable or not. While the framework currently makes

provision for such feedback and appropriation, it has not been fully investigated or evaluated with the device.

Area 5: Facilitate sharing strategies to build capabilities, recognise progress and support others

Sharing information and strategies with others with CP is a way to recognise progress in oneself and support others and is encouraged in pain management programmes as discussed in Chapter 2 and 7. Some people may avoid movement or making changes to their routine for fear of exacerbating pain. However, if they can apply the strategies that other people may have developed, they could potentially use them to start exploring their body.

Further, sharing strategies would generate discussion about how people use their bodies to do activities and sharing tips which could help to provide tangible support that is sometimes lacking after pain management programmes. There is space to investigate if and how people share SMSs that they design and how these can be adapted by others, particularly, what information should be shared, how it can be shared and what tools are needed to personalise others' SESs and SMSs to make them useful for others to self-manage their activity.

Area 6: Facilitate other exercises besides reaching and bending

Currently the device sonifications for Go-with-the-flow have only been tested for reaching forward and bending exercises. While the sonifications can also be used for other exercises where bend angle changes, we have not tested the sonification conditions. The sonification framework could also be extended to other exercise situations that do not involve bend angles, but this needs investigation.

14.3.2 Applying Go-with-the-flow and RaFT frameworks beyond physical rehabilitation in CP

We argue that both the frameworks could be applicable beyond the scope of CP rehabilitation, to other areas of physical activity and motor rehabilitation.

We argue that it could, potentially be applied to many other applications such as physical rehabilitation in other conditions of limited mobility, building awareness of activity in healthy populations when learning new tasks, people recovering from injury or practicing physical therapy exercises.

The RaFT framework could also be applied in other rehabilitation technologies to provide more focus on psychological factors and functioning in everyday and ubiquitous contexts. Further research is necessary to discover how far the factors in both the frameworks proposed in this

thesis can be applied to other motor-learning applications, and whether new factors need to be added to this model to make it more versatile.

14.4 Thesis summary

The research presented in this thesis is centred on developing technology to support self-managed physical rehabilitation of people with CP. In this thesis, we focused on rethinking technology design for physical activity in CP by addressing psychological barriers in self-directed activity. We also focused on facilitating functional activities rather than just exercise and providing people with tools to rediscover and enhance their capabilities, beyond motivation. We made five main contributions to the literature by, (i) providing an in-depth understanding of barriers and strategies in CP physical rehabilitation, (ii) conceptualising a sonification framework, *Go-with-the-flow*, and wearable device to facilitate physical activity in people with CP, (iii) extending our sonification framework for facilitating home-based functional activity using a sensing device, (iv) proposing a framework to facilitate design of rehabilitation technologies (RaFT), and, (v) providing insights on the role of empathy and practical guidelines for doing sensitive research. We finally provided several exciting directions for future work in this area.

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Appendices

Appendix A. Information sheets and consent forms

A.1 Sample Information Sheet for UCL Ethics

Information Sheet for Participants in Research Studies

You will be given a copy of this information sheet.

Title of Project: **Emotion & Pain Project**

This study has been approved by the UCL Research

Ethics Committee [Project ID Number]: **STAFF/1011/005**

Name, Address and Contact Details of Investigators: Dr Nadia Bianchi-Berthouze
UCL Interaction Centre
MPEB 8th floor
University College London
Gower Street
London WC1E 6BT
United Kingdom
+44 (0)20 7679 0690

We would like to invite you to participate in this research project. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or you would like more information.

This project aims develop healthcare technology to help patients with chronic pain by providing feedback on their movement performance and psychological support during self-directed rehabilitation.

We will be interviewing you to gather the needs for such technology. We may also ask you to try current available technology to motivate and measure patients' physical and psychological state. Hence we may ask you to play computer games and wear biosensors. The activity may be recorded using motion capture technology or video/ audio recording. We may also ask you to fill in a questionnaire

All data will be handled according to the Data Protection Act 1998 and will be kept anonymous. Researchers working with Dr Nadia Berthouze will analyze the data collected. The information gathered will be used to understand chronic pain patients' requirements for physiotherapy technology.

With your permission, we would like to use extracts of the video recording to demonstrate to chronic pain patients how assistive technology can be used for the management of their condition.

With your permission, we may want to use an extract of the video recording for teaching, conferences, presentations, publications, and/or thesis work.

It is up to you to decide whether or not to take part. If you choose not to participate it will involve no penalty or loss of benefits to which you are otherwise entitled. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

All data will be collected and stored in accordance with the Data Protection Act 1998.

Researcher Notes, Optional Clauses:

- If you do decide to take part, please let us know beforehand if you have been involved in any other study during the last year.

A.2 Sample Consent Form for UCL Ethics

Consent Form

Title of Project: **Emotion & Pain Project**

This study has been approved by the UCL Research Ethics

Committee [Project ID Number]: **STAFF/1011/005**

Participant's Statement

I

agree that I have

read the information sheet and/or the project has been explained to me orally;

had the opportunity to ask questions and discuss the study;

read the guidelines on the use of computer game used for the study;

received satisfactory answers to all my questions or have been advised of an individual to contact for answers to pertinent questions about the research and my rights as a participant and whom to contact in the event of a research-related injury.

I understand that my participation will be taped/video recorded and I am aware of and consent to the analysis of the recordings.

I understand that I must not take part if I am not physically able to do the tasks

I agree to be contacted in the future by UCL researchers who would like to invite me to participate in follow-up studies.

For the following, please circle "Yes" or "No" and initial each point.

____ I agree for the videotape to be used by the researchers in further research studies YES
/ NO

____ I agree for the videotape to be used by the researchers to demonstrate assistive technology to chronic pain patients YES / NO

____ I agree for the videotape to be used by the researchers for teaching, conferences, presentations, publications, and/or thesis work YES / NO

I understand that I am free to withdraw from the study without penalty if I so wish and I consent to the processing of my personal information for the purposes of this study only and that it will not be used for any other purpose. I understand that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.

Signed:

Date:

Investigator's Statement

I

confirm that I have carefully explained the purpose of the study to the participant and outlined any reasonably foreseeable risks or benefits (where applicable).

Signed:

Date:

A.3 Sample Information Sheet for NHS Ethics

Reference: IS-1 (Information sheet for interviews with people with chronic pain)

UCL Project ID number: 10/0514

REC number:

Form version: 1.0

Date: 14/12/2011

1. Study title

Automated psychological & physical feedback for chronic pain rehabilitation

2. Invitation paragraph

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

3. What is the purpose of the study?

The influence of pain on everyday life can be considerable. Pain is a complex and intense experience affecting the way we feel, move and approach different situations. This project aims to develop a technology to encourage people with chronic pain to do more physical activity and give feedback on the activity. To do this we need to better understand how pain affects your physical activity in daily life through interviewing you.

4. Why have I been invited?

We are asking people with chronic low back pain to volunteer for this study.

5. Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and you will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the care you receive.

6. What is involved in the study?



UCL Hospitals is an NHS Foundation Trust incorporating the Eastman Dental Hospital, Elizabeth Garrett Anderson & Obstetric Hospital, The Heart Hospital, www.uclh.nhs.uk for Tropical Diseases, National Hospital for Neurology & Neurosurgery, The Royal London Homoeopathic Hospital and University College Hospital.



This project aims develop healthcare technology to help patients with chronic pain by providing feedback on their movement performance and psychological support during self-directed rehabilitation.

We will be interviewing you to understand the needs for such technology.

7. What are the possible benefits of taking part?

There is no direct benefit to you from taking part in this study: we are asking you to do it to help design a technology to support and motivate physical activity in people with chronic pain.

8. How will Information be kept?

A unique research ID number will be assigned to the information we collect from you, and any personal identifiable information, such as your name and data of birth, will be in a separate file and not linked directly with the rest of the information.

All the information collected will be treated according with the Data Protection Act 1998 and UCL Data Protection Act Policy 2000 (<http://www.ucl.ac.uk/efd/recordsoffice/data-protection/>). Paper records will be stored in locked filing cabinets. Digital information (e.g. your interview audio recording) will be stored in password protected and secure computers to be used by researchers involved in the project.

9. What if something goes wrong?

Every care will be taken in the course of this study. However, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated by members of staff or about any side effects (adverse events) you may have experienced due to your participation in the study, the normal National Health Service complaints mechanisms are available to you. Please ask to a member of the research team if you would like more information on this. Details can also be obtained from the Department of Health website: <http://www.dh.gov.uk>

10. What will happen to the results of the research study?

This research project is 4 years long, and we would hope to publish and disseminate the results, or to present them at conferences, during and after the project. During the dissemination process no patients' names will be disclosed either in publications or in conferences. If you would like us to send you a summary of our findings, please give us a mailing or e-mail address so that we can do so.

11. Who is organising and funding the research?



The research is funded by The Engineering and Physical Sciences Research Council (EPSRC) grant to Dr Berthouze at UCL.

12. Withdrawal from the project

Your participation in this study is entirely voluntary. You are free to decline to enter or to withdraw from the study any time without having to give a reason. If you choose not to enter the trial, or to withdraw once entered, this will in no way affect your future medical care. All information provided will be treated as strictly confidential and will only be used for medical purposes. Participation in this study will in no way affect your legal rights.

13. Who has reviewed the study?

The study has been reviewed and passed by the UCLH Research Ethics Committee and the Engineering and Physical Sciences Research Council (EPSRC).

14. Contact for further information

If you want any further information about the study, please contact:

Dr Nadia Berthouze 020 7679 0690 n.berthouze@ucl.ac.uk

Dr Amanda Williams 020 7679 1608 amanda.williams@ucl.ac.uk

Aneesha Singh 020 7679 0683 (x30683) aneesha.singh.10@ucl.ac.uk

Or visit the project website: <http://www.emo-pain.ac.uk>

Thank you for taking the time to read this information sheet and considering taking part in the study.

A.4 Sample consent form for NHS ethics

University College London Hospitals 

NHS Foundation Trust

Centre Number:
Patient Identification Number for this study:
UCLH Project ID number:
Form version: 1.0
Date:

Pain Management Centre
National Hospital for Neurology & Neurosurgery
Queen Square, London WC1N 3BG
Telephone: 0845 155 5000 ext 72-3487
Fax: 020 7419 1714
web-site: www.uclh.nhs.uk

CONSENT FORM part 1

Title of project: **Automated psychological & physical feedback for chronic pain rehabilitation**

Name of Principal Investigator: Dr Nadia Berthouze

Please initial box

1.	Iconfirm that I have read and understood the information sheet dated xx/xx/xxxx (version 1.0) for the above study and have had the opportunity to ask questions.	
2.	I confirm that I have had sufficient time to consider whether or not I want to take part in the study	
3.	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	
4.	I agree that the exercise session can be observed and paper notes can be taken YES/NO	
5.	I agree to take part in the above study	

Participant: _____ Date _____ Signature _____

Person taking consent: _____ Date _____
Signature _____

Dr Nadia Berthouze Date _____ Signature _____
Researcher (to be contacted
(if there are any problems)

Comments or concerns during the study

If you have any comments or concerns you may discuss these with the investigator. If you wish to go further and complain about any aspect of the way you have been approached or treated during the course of the study, you should write or get in touch with the Complaints Manager, UCL hospitals. Please quote the UCLH project number at the top of this consent form.

Appendix B. Part 1- role-plays

B.1 Guide for role-play studies

Topic/aim	Description
Setting	Conduct role-play in physiotherapist's office as a first/second consultation between the physiotherapist and patient with CP.
Patient persona	A patient with lower back pain for a number of years.
Situations	<p>Model a first and second consultation with physiotherapist</p> <p>First consultation:</p> <p>Interact with physiotherapist; what do they ask/ do in initial meetings. Get exercise prescribed for low back pain.</p> <p>Second consultation:</p> <p>Feedback from physiotherapist for:</p> <p>Doing prescribed exercises well. (Check for feedback/ facial expressions/ cues; further recommendations for exercise)</p> <p>Reluctance to do prescribed movement due to</p> <p>Fear/ anxiety/ worry about pain/ damage</p> <p>Lack of time/ practical concern</p> <p>Tiredness after first time doing the movement</p> <p>Inability to do the movement</p> <p>Trying to show that the movement causes additional discomfort and pain</p> <p>Show the physiotherapist the movement but do it slightly wrong or as if in pain</p> <p>Ask the physiotherapist to demonstrate the movement</p>
Prompt if:	If the physiotherapist uses cues from the environment/ suggests cues
Observe and note	Facial expressions and non-verbal behaviour/ language for communicating with people with CP, especially when displaying pain.

Appendix C. Part 1 - interviews

C.1 Details of interviewees with CP in interviews conducted in Phase 1 study

PCPI#	Age	Sex	Years CP	Physiotherapy / PMP
PCPI1	50	F	30	Ongoing
PCPI2	51	M	23	X2 (22 y ago)
PCPI3	28	F	17	No PMP; Physiotherapy: 10-15 years ago
PCPI4	36	M	4	No PMP
PCPI5	56	F	26	Yes (several)
PCPI6	46	F	38	1 week ago
PCPI7	57	M	4	
PCPI8	58	M	20	18 years ago
PCPI9	31	F	16	6-8 months ago
PCPI10	53	M	15	AS treatment
PCPI11	52	F	5	6 months ago
PCPI12	48	F	5	Y (cant remember)
PCPI13	19	M	5	N (seen consultant)
PCPI14	37	F	18	2 years ago
PCPI15	25	F	14	N
PCPI16	74	F	37	N

C.2 Interview guide for people with CP

Topic	Description
Pre-interview	Pre-Interview: Can you write explaining about what physical activities you do not do any longer because of pain?
Introduction	Introduction to the person being interviewed. Aims to find out about them (age, occupation), their pain (duration of CP, location of CP), pain management experience (if they did a PMP, or saw a physiotherapist for CP, how long ago)
Physical activity	Typical activities in a day (including exercises and functional activity), Other fitness activities/ exercise; probe details. (If they do not do much physical activity) Did you do many fitness activities before the pain started? Can you say why you stopped? Strategy for physical activity on average and difficult pain days Preferred physical activity (could they do this despite pain/ modifications because of

Topic	Description
	<p>pain/ reasons if they could not do it/ needed to modify it)</p> <p>Strategies to make typical/ preferred activities easier</p> <p>Group fitness/ activity classes or drop in physiotherapy sessions – what support they provide? Are they useful? How can they be improved?</p> <p>(if not answered in question above) – Do you do any stretching or relaxation exercises?</p> <ul style="list-style-type: none"> - What kind of support do you want from a coach or physiotherapist while you are doing physical exercises or stretches? - Alternate question: Can you tell me of any experience with a teacher/ friend/ coach that you found motivating/ supportive. What did they do that you liked and found motivating? What is the most useful tip related to physical activity that has been given to you? - What kind of support do you want from a coach or physiotherapist during relaxation (physical/ psychological)? What would be useful for you to know while doing physical activity – about the activity and about how you do it? <p>(if not answered in question above) – Do you do any stretching or relaxation exercises?</p> <ul style="list-style-type: none"> - What kind of support do you want from a coach or physiotherapist while you are doing physical exercises or stretches? - Alternate question: Can you tell me of any experience with a teacher/ friend/ coach that you found motivating/ supportive. What did they do that you liked and found motivating? What is the most useful tip related to physical activity that has been given to you? - What kind of support do you want from a coach or physiotherapist during relaxation (physical/ psychological)? What would be useful for you to know while doing physical activity – about the activity and about how you do it? - (if class/drop in session): what support does the class/ drop in session offer you? Do you think this could be better/ improved in any way?
Mood	<p>(if they mention mood) Does your mood affect whether you do physical or relaxation activities? Does it affect which activity you choose to do? Or whether you choose to carry on or give up the activity?</p> <p>How do you vary your routine? Do you choose what activity to do yourself or do you need a physio or friend to suggest them? Does your mood affect the kind of support you want from a coach/physiotherapist?</p>
Rewards/ motivation	<p>Is there anything that makes you feel particularly good or satisfied about an exercise session?</p> <p>Do you reward yourself/ set incentives for achievements in physical activity? Can you tell me about that?</p>
Social	<p>Do you exercise with someone else/ share achievements with friends/ an exercise partner/buddy?</p>
Technology	<p>Do you use any social networks? Do you share your achievements socially?</p> <p>Do you use a smartphone or any social networking websites like Facebook? (If they do) Do you use any games/ apps on the phone/ site e.g. Angry birds, Farmville, etc? What (features/ incentives) motivates you to use these apps?</p> <p>Do you ever play video games like Wii/ Kinect/ etc?</p> <ul style="list-style-type: none"> • How often do you use it or what kind of exposure do you have to it? • Do you think an instructor in a video game setting could be motivating or support you in doing exercises/ physical activity? What kind of support do you think such an instructor could provide that would help? <p>Do you think it would be helpful if the technology provided you with feedback on</p>

Topic	Description
	<p>your physical activity? What kind of feedback would you find helpful?</p> <ul style="list-style-type: none"> • How would you like to see the feedback represented (think about games already played?) • Would you like to see a representation of yourself doing physical activity – what form would you like this to be (animated/ real/ blurred shadow)? • What kind of information would be useful for you to know from technology about your history of exercise? • Would it be helpful for the technology to recognize and adapt to your mood/ level of pain? How would that help you?
Optional questions (if they mention movement/ avoidance and balance issues)	<p>How you feel pain affects the quality of your movement/ the way you move?</p> <p>Are there/ were there specific movements that you have difficulty with since the pain started? How do you feel that they could be/ have been helped by a physiotherapist/ programme of physical activity?</p> <p>Do you feel a sensor that judges the activity you do and shows you the results through feedback(visual/ audio) would be helpful?</p>

C.3. Interview guide for physiotherapists

Thank you for agreeing to talk to me. As you know, this project is about developing healthcare technology to support people with chronic musculoskeletal pain to carry out physical activity. If you have any questions about the project at the end, I will be happy to answer them.

Before starting the interview, I'd like to confirm that it's okay to record our conversation. This is just so that I can go back to it later for my research. It will not be used for any other purposes.

I would like to ask you some questions about yourself before we start. If you feel uncomfortable answering any of the questions, please let me know and we can go on to the next question.

General interview questions:

- How long have you worked with people with chronic pain?
- What do you perceive are the main determinants of physical activity in this population?
- What do you try to determine about a person's physical activity needs in a typical session? The first time you meet a person with chronic pain? How do you follow up this treatment in following sessions? What do you concentrate on? How do you encourage people to continue with a regime even if they may be having problems – do you have a strategy?
 - How do you decide what kind of exercise would be suitable and what kind of encouragement to provide people?
 - How do you match goals to exercises?

- What are the most typical challenges that you think are faced by people with chronic pain? Do they have any strategies they use to deal with pain? Are these sometimes detrimental?
 - Do you think there is a trigger that can cause people to do more activity?
 - (If they do not do much physical activity) What are the most common reasons that people stop doing activity, besides the pain?
 - Optional: What strategy do you prescribe for physical activity on average days and difficult days?
- If people have a preferred physical activity (eg gardening, fishing, walking, yoga, swimming) that they do not do anymore because of pain, how do you encourage them to do them again? Do you tell them a way to make it easier? *Such as stretching, relaxing, breaks, sitting rather than standing?*
 - *Optional: Do people generally feel the need to do more physical activity? What do you think would be motivating for them to achieve/ maintain that level? What holds them back?*
- *What kind of support can they get from a physiotherapy session that they find useful? give you/ do you find those useful (friend, partner, peer)– why? How can it be better?*
 - *What do you watch out for when looking at a person with chronic pain doing exercises? How do you give them feedback?*
 - What kind of stretching and relaxation exercises do you prescribe to patients? Are they always related to a goal? How do you modify the prescribed plan in subsequent session based on progress or lack thereof? How do you track improvement/progress? How do you support disappointment?
 - What kind of support do you give while people are doing physical exercises or stretches?
 - Alternate question: Can you tell me of any time that a patient told you something they'd been told by you or another that changed their attitude to pain/exercise? What do you do for motivating people with pain to do activity? What do you think is the most useful tip related to physical activity?
 - What kind of support do you give during relaxation (physical/ psychological)? What would be useful for people to know while doing physical activity – about the activity and about how they do it?
- (if class/drop in session): what support does the class/ drop in session offer people? Do you think this could be better/ improved in any way? How do you cater to people with different abilities in these sessions?
- Does people's mood affect whether they do physical or relaxation activities? Does it affect which activity they choose to do? Do you think there is a strategy to choosing activity for this? Do you advise patients about this?
- How do you make people vary their routine to avoid boredom? Do you choose suggest detailed plans?
- Do you suggest a strategy for reward / set incentives for achievements in physical activity to your patients? Can you tell me about that?
- Do many people exercise with someone else/ share achievements with friends/ an exercise partner/buddy? DO you recommend that?

Technology questions

- Do you use any social networks? Do you have any chronic pain groups?
- Do you use a Smartphone or any social networking websites like Facebook? (If they do) Do you use any games/ apps on the phone/ site e.g. Angry birds, Farmville, etc ? What do you think of the features/ incentives on these apps?
- Do you ever play video games like Wii/ Kinect/ etc? How often do you use it or what kind of exposure do you have to it?
 - Do you think an instructor in a video game setting could be motivating or support people in doing exercises/ physical activity? What kind of support do you think such an instructor could provide that would help?

- Do you think it would be helpful if the technology provided feedback on physical activity? What kind of feedback do you think would be helpful?
- Do you think it would be helpful for the technology to track progress, perhaps?
- Would you like the feedback to be in the form of a graph?
- Would people like to see a representation of themselves doing physical activity – what form this be useful (animated/ real/ blurred shadow)?
- What kind of information would be useful for people to know from technology about their history of exercise?
- Would any of this information be useful to you?
- Any other way technology can help?

C.4. Technology habits of interviewed people

P#	Twitter	Facebook	Websites	Forums and groups	Smartphone and tablet games	Smartphone apps	Wii/Kinect/PS3 games	Pedometers	DVDs	Comments
No. of users	5	9	15	7	5	5	1	2	1	
1								✓		Prefers books
2			✓	✓						
3			✓							
4			✓							
5		✓	✓*							*Ebay, dating sites
6		✓	✓*	✓	✓**	✓**				*CP group on facebook based in Reading; ** CP app with daily stretches; Games: Bejewelled, pacman
7			✓							
8	✓	✓	✓	✓				✓		Runs a website for CP self-management.
9		✓	✓	✓						Online group on Facebook called Chronic pain lifeline. Chronic pain tracker app. Games: Angry birds, Zombie farms, Cut the rope. Movement games: Tai chi, Raving rabbids, Kinect sport
10	✓	✓	✓	✓	✓	✓	✓			Movement games: Tai chi, Wii. iPhone tracker app
11		✓	✓			✓	✓			Games: Bejewelled; Movement games: Wii fit, Balance board, dance
12	✓	✓	✓				✓			Movement games: has played but does not like them.
13			✓		✓					Games: Card games. Aware of most of the technology but does not like using it.
14		✓	✓	✓	✓	✓				App: back-care; Games: Mah jong
15	✓	✓	✓	✓	✓	✓	✓			Plays Kinect games but dislikes them
16	✓		✓						✓	Runs pain management website

Appendix D. Part 1 - focus groups

D.1 Script for focus group 1

Thank you all for coming today! It is wonderful to see you all and I'm hoping for a great discussion. As you all know this focus group is part of the Emotion and Pain project between UCL, Imperial and Leicester Universities. My aim in doing these studies is to understand how technology can be used in motivating and supporting physical activity in people with chronic pain. In order to understand this better, I need to understand how you currently manage to adjust your activity around the limitations imposed by pain, and what would help you. In particular, I am interested in what would help them which physiotherapists – or even personal trainers or sports trainers - have offered in the past but cannot offer long term, to help maximise fitness and strength and flexibility within the constraints of pain.

So I'll be asking about how you organise things now, what you use to help you, and what you can imagine or visualise which can further help as well. If you have any questions during or after the focus group, I am happy to answer them. Also, to set some ground rules about the focus group, which I am sure are unnecessary but I'll just go through them:

- What gets discussed in the room stays in the room; what any participant says during the discussion or the identity of any individual present once they leave the focus group site.
- Please give everyone a chance to speak without being interrupted. Everyone is free to express their opinions without fear of being judged or attacked by the group.

Further, before we start, I'd like to say please feel free to stand up and walk around at any point. Restrooms are located in the basement. The lift across the corridor will take you there. If the fire alarm goes off we need to leave immediately via the main entrance. I'd like to propose a round of introductions. Please do not use your last names. We will do the 30 second introduction where you say who you are, if there is anything you'd like to share about yourself or your pain or anything else you think is interesting about you. Only limitation is keeping it to 30 seconds.

Since we are talking about physical activity, do you think it is helpful to divide physical activity into essential everyday stuff (showering/bathing, dressing, essential shopping, essential housework, making meals and clearing up, etc.), extra everyday stuff ("spring cleaning", bigger shopping tasks e.g. for major household items, etc.), and stuff that doesn't have to be done to survive but they really want to do and are part of normal life – socialising, working/voluntary work, evening classes or pursuing hobbies or interests, etc.

1. Do you have a routine for doing stretching or exercise, or do you cover it by everyday activities (and then ask a bit about those.)

- a. Do you plan activities/ your day in advance? Do you compensate for special activities?

3. What differences/ gaps do you perceive:

- While doing activity with someone else (like physiotherapist) vs on your own
- Away from the house vs in the house. (away from the house, therefore can't so easily stop and take a break)?

4. What kind of support do you find useful for physical activity? Additional to what is already available to you, what support would you find useful to support physical activity, e.g. a reminder, timer, tracker ... *(What kind of feedback do you find from physios/ family? What do you feel would help additionally)*

- Is there anything that someone in your family does (emotionally or physically) that supports your physical activity?
- Or vice versa, is there anything that someone in your family or household does that stops you?

5. Do you think that your movement should be corrected? Can you tell me about that? Is there a point where you think you should be stopped or do you prefer to always control your level of activity?

6. Do you have worries about doing a particular physical activity?

Prompt: Are there any strategies that you use to make physical activity easier?

7. When you are away from home for a day or more, do you have a strategy for continuing your stretches or activity?

8. Do you keep track of how much activity you have done over a period of time? Do you find it useful to keep track?

9. In the videos I sent you, what did you think of the trainer? Also, what did you think of the way in which the person doing the exercise was represented? What kind of incentives would be useful?

Any final thoughts?

Thank participants.

D.2 Script for focus group 2

This document contains:

- a. Focus group introduction
- b. Focus group questions (to be used by moderator)
- c. General questionnaire (for participants)

Script for opening the session

'Welcome to our focus group. Thanks for taking the time to join us and talk about patient centred computer technology for people with chronic pain. We will introduce ourselves .(briefly mention name and role in the project)

We can start by providing a little information about the project and what we are hoping to develop and how you can help.

At present we are designing and developing psychological health technology that will support people with chronic pain in performing physical activity to manage their pain. We need your views on what would make it more helpful for you to use, which is why we are here today.

We will ask you all, as a group, open-ended questions and you can discuss your answers with us and amongst the group. There are no right or wrong answers. Please feel free to share your point of view even if it differs from what others have said. We're just as interested in negative comments as positive comments. We are here to guide the discussion to ensure that all the topics are covered, everyone has a say and to guide the timing of each question and answer.

As you may have noticed, we are video and audio recording the session because we don't want to miss any of your comments. Therefore it would be helpful if only one person could speak at a time. People often say very helpful things in these discussions and we can't write fast enough to get them all down. Today, we will be on a first name basis, although we won't use any of your names in our reports. Therefore you can be assured of complete confidentiality. We've placed name cards on the table in front of you to help us remember each other's names. The reports will go back to our research team to help design the technology'

'If people have ideas that they cannot communicate at that time, maybe since someone else is having their say or we have run out of time, please make a note of them. You can maybe mention it later or chose to give us your ideas at the end.'

'Please could everyone put their mobile phones on silent'.

Focus group questions

- What kind of support do you find useful for physical activity (stretching/ exercise) from physios/family?
- What strategies do you find useful for doing more physical activity? (Prompt: Mirror)
- Do you generally do stretches/ exercise with a goal in mind? (E.g. of goal).
- Secondary q: How do you reward yourself when you reach the goal?
- What physical activity/ stretches etc do you find most useful and do most often?
- Secondary q: Do you keep track of how much activity you've done?
- Are there any activities/ particular movements that you used to avoid in the past that you do not anymore? (Prompt: How did you overcome that?)
- What technologies do you currently use for recreation/ supporting your activity/ pain e.g. smartphone apps (Prompt: e.g. a reminder, timer, tracker)

Questions for video demos:

- *Any initial thoughts?*
- *What did you think of the*
 - *Virtual coach?*
 - *Exercise demonstration and instructions?*
 - *Information about activity reflected in the programme?*
 - *Visual components of the programme?*

General Questionnaire

Participant Identifier: (to be filled in before the focus group)

- Age
- Gender:
- Number of years you've had chronic pain:
- Have you seen a physiotherapist or been to a pain management programme where they had physiotherapy or an exercise component?
- If you answered yes to Q4, can you tell us what year you attended?
- Do you have a smartphone?
- If yes, do you use it to play games or for pain management apps? Which ones?
- Have you used movement video games (like Wii/ Kinect)?
- Which video games did you use?
- Did you find them useful/ engaging?

Thank you for your time.

D.3 Focus group participants use of technology

Focus Group1

P#	Smartphone	Apps	Movement games	Video games
1	Y	N	N	N
2	N	N	N	N
PT1	Y	Mindfulness	N	N

Focus Group2

P#	Smartphone	Apps	Movement games	Video games	
1	Y	N	N	N	
2	N	N	N	N	
3	Y	N	N	N	
4	Y	N	Y (Wii fit/ sport)	N	Ok to a point
5	N	N	Y(Wii fit)	N	Not engaging

6	N	N	N	N	
7	Y	N	N	N	
8	N	N	N	N	
9	Y	None	Y(Wii fit)	N	Find movement games engaging
10	Y	Many	Y (Kinect sports)	N	Not engaging; hurts to use the movement games
11	Y	Pain tracker	Y (Wii for rehab in hospital: balance and sport)	Y	Movement games expensive
12	N	N	N	N	
13	N	N	N	N	
14	N	N	N	N	
15	N	N	N	N	
16	Y	-N	Y(Wii, Kinect)	N	Yes but difficult
17	Y	Games, shopping apps, google	Y(Wii): Wii fit plus, Wii sports	N	Movement games engaging
18	N	NA	N	N	
19	N	NA	N	N	
20	Y	Solitaire	N	N	

Appendix E. Part 2- Study protocol

E. 1 Focus group –

Go with the flow 6th October 2014 at 12:30

Duration: 1h30m + lunch

Number of participants – 6 people with CP

Preparation

- Book room
- Book lunch and refreshments
- Tea, coffee, water – 12
- Lunch – 13:30
- Paperwork
- Consent forms and information sheets
- Note-taker forms
- Observation sheets
- Expenses form

Equipment

- 2 cameras
- 2 voice recorders
- Kinect setup
- Smartphones with apps loaded
- Picture cards with recorded audio of sounds in the app and Kinect
- Electronic keyboard
- Arduino, jacket, etc.
- Batteries
- Splitters
- Headphones
- EMG
- Paper and pen and post its for participants
- Name-tags (with only first names) for all present
- Cash for expenses
- Pre-focus group questionnaire
 - b. Are there any household or other activities/ stretches that you worry about and hence do not do at all or as much as you'd like?

- c. Do you think that the sounds that were used in the earlier study to give information about your movement (stretch forward/ sit to stand) can help? Could you tell me a bit about that?
- d. Are there any other sounds that you would use instead of the ones used in the study that you would find motivating/ relaxing while doing physical activity or stretches – could you please get some examples of music you like, if possible, or tell us what you like and we can get the music.
- e. Do you generally use music to stretch?
- f. Focus group script and questions

Thank you all for coming today! It is wonderful to see you all and I'm hoping for a great discussion.

As you all know this focus group is part of the Emotion and Pain project between UCL, Imperial and Leicester Universities.

Our aim in doing these studies is to understand how technology can be used in motivating and supporting physical activity in people with chronic pain. You have already tried some of the technology in this room that we have designed for the purpose of better understanding how we can achieve this through the use of sound to give information about your movement. As you can see there are technologies available to try in this room and we will split into pairs to discuss some of these and then reconvene for a further discussion but I will tell you more about this as we go on.

So I'll be asking about if you can visualise using these tools, how you would use them, and what you imagine can further help as well.

If you have any questions during or after the focus group, I am happy to answer them. Also, to set some ground rules about the focus group, which I am sure are unnecessary but I'll just go through them:

- What gets discussed in the room stays in the room; what any participant says during the discussion or the identity of any individual present once they leave the focus group site.
- Please give everyone a chance to speak without being interrupted. Everyone is free to express their opinions without fear of being judged or attacked by the group.

Further, before we start, I'd like to say please feel free to stand up and walk around at any point. Restrooms are located [XXX]. If the fire alarm goes off we need to leave immediately via the main entrance [In case of fire instructions]. Please help yourself to tea and coffee. Lunch is here but we can start around 13:15 and we can have a short break then as well.

I'd like to propose a round of introductions. Please do not use your last names. We will do a 30 second introduction where you say who you are, if there is anything you'd like to share about

yourself or your pain or anything else you think is interesting about you. Only limitation is keeping it to 30 seconds. I can start with myself. [Introduce self]. End by introducing other researchers and physio.

Activity 1:

2. So we asked you about the activities that you felt could benefit from the music feedback we gave you during the study or any music that you stretch to/ enjoy.

<If they send us this information> What came out from your answers was What do you think ...? ...

<If they do not send this information> So what are some activities ... sounds ...<go around the table>.

3. What sounds could make the activity easier?
4. What sound would motivate them to do this activity?

Activity 2: 10 mins for the activity followed by discussion

Split people into threes to explore the smartphone with activity they worry about. We will provide straps to strap the phone to the body. Followed by discussion and header questions:

1. How do you define your exercise space? (anchor points)
2. What would you like the sound to convey about your movement?
3. (Holding the stretch? How far you've stretched? Etc)
4. What would you like to sonify?
5. Muscles? Breathing? Something else?

Activity 3: 10 Explore the sounds and Kinect

1. Which sounds did you like on the Kinect and why? (offer to try)
2. How would you use the three different sounds?
3. Would altering the sound based on your movement be useful?

Other questions:

- Does it matter where the sound is coming from? How does that affect you?

E.2 Study protocol for control study

- Glossary: PCP- Person with chronic pain.
- Number of researchers – 3
- Study organised in UCLIC big lab
- One person to operate EMG.

On arrival of PCP:

Offer tea/ refreshments.

Explain study/ give time to read information sheets/ get consent forms signed

Fill in questionnaires –

- a. Demographics
- b. Medical history and pain medication.
- c. Self-evaluation (STAI)
- d. Work and social adjustment scale (WSAS)
- e. HADS
- f. Physical activity questionnaire
- g. Pain catastrophising scale
- h. Pain rating scale
- i. Pain NRS

Wear jacket with breathing sensors and arduino

Wear EMG

Conducting the study:

Study 1: Kinect

Conditions:

2 types of stretches; 3 counterbalanced conditions, with parameters specified –

- Use randomized sequence in table below.

1. Stretch forward

- (i) Tones of sound
 - a. Bell shape [Cello]
- (ii) Active music listening
 - a. Linear rising [Music: Friends]
- (iii) Active icons
 - a. Linear rising [Wood]

2. Sit-to-stand

- (i) Tones of sound
 - a. Bending phase: Bell shape [Piano]; Lifting up phase: Linear rising [Cello]
- (ii) Active music listening
 - a. Bending phase: Linear rising [Music: Friends]; Lifting up phase: Linear rising [Music: Friends]
- (iii) Active icons
 - a. Bending phase: Linear rising [Wood]; Lifting up phase: Linear rising [Wood]

For each condition:

Before starting: ask pain and anxiety level

Step 1: Calibration (no sound)

Step 2: Exploratory stretch:

The person will be told the sounds and asked to speak aloud while stretching about what they are feeling in terms of the stretch and what they can hear (music sounds). Ask pain level after each condition.

Step 3: We will give them information about the sounds and they will repeat the stretch. Step 3 will be repeated twice. Ask pain and anxiety level after each condition.

Study 2: Smartphone

Stretches: 2 types –

- (i) Stretch forward
- (ii) Bend forward

Conditions: 5 counterbalanced conditions –

- (i) No sound
- (ii) Wave sound
- (iii) Flat sound
- (iv) Water
- (v) Windchimes (No target)

For each condition:

Step 1: Calibration (no sound)

Step 2: Exploratory stretch:

We will not give the person any information about the sounds. The person will be asked to speak aloud while stretching about what they are feeling in terms of the stretch and what they can hear (music sounds).

Step 3: We will give them information about the sounds and they will repeat the stretch. Step 3 will be repeated twice.

Step 4: They will be asked to calibrate their target by reaching for an object from a shelf. They will then do the stretch.

After each step they will be asked about their perceived stretch and pain level.

After each condition, they will be asked how hard they found it to stretch.

- Compare no sound, wave vs. flat sound with set target
- Compare (favourite between: wave, flat sound) with breathing no breathing
- Compare (favourite between: wave, flat sound) in real target vs set target

Explore all various sounds in a qualitative manner

Sequence of conditions for each PCP (Generated from <http://www.randomizer.org/form.htm>)

PCP#	Kinect: stretch	Kinect: sit to stand	Gwtf: stretch	Gwtf: bend
1	3,2,1	3,1,2	4,5,1,2,3	1,4,5,2,3
2	1,3,2	2,1,3	1,4,5,2,3	1,2,5,4,3
3	3,2,1	2,1,3	5,2,1,4,3	1,5,2,3,4
4	3,2,1	3,1,2	3,3,2,4,1	4,2,1,5,3
5	2,1,3	3,1,2	4,3,1,5,2	2,4,3,5,1
6	2,3,1	2,3,1	3,4,5,1,2	5,3,1,2,4
7	2,1,3	2,1,3	5,3,1,2,4	5,4,2,1,3
8	1,3,2	1,2,3	1,5,2,4,3	3,1,5,2,4
9	3,1,2	1,3,2	3,5,4,1,2	3,4,5,2,1
10	2,1,3	2,3,1	2,3,4,1,5	5,4,1,2,3
11	3,1,2	3,2,1	3,4,5,2,1	2,4,1,3,5
12	3,2,1	2,1,3	3,5,2,1,4	3,1,4,2,5
13	1,3,2	3,1,2	3,2,1,5,4	1,3,2,5,4
14	3,1,2	2,1,3	3,5,4,1,2	3,4,1,5,2
15	2,1,3	3,1,2	1,4,2,5,3	3,4,1,2,5
16	3,2,1	1,3,2	5,3,1,2,4	1,2,4,5,3
17	1,2,3	3,1,2	5,3,2,1,4	1,5,4,2,3
18	3,1,2	1,2,3	4,3,5,2,1	5,3,4,1,2
19	1,2,3	3,2,1	5,1,4,2,3	3,4,1,2,5
20	1,2,3	2,1,3	2,3,5,4,1	5,4,2,1,3

Appendix F. Additional details of statistical comparisons of sonification effects from the *Go-with-the-flow* evaluation study

F.1 Effect of different levels of sound information on exercising

Table F.1 Results from statistical comparisons between the sound conditions (different amounts of information) on perceived and actual bend angle during reach forward exercising using the wearable device. Bonferroni correction was applied to multiple comparisons ($p=0.008$ corresponding to a significance level of $\alpha=0.05$). Non-significant comparisons are marked as n.s.

Measure	Friedman tests ANOVA	Wave vs. No sound	Water vs. No sound	Flat vs. No sound	Wave vs. Water	Wave vs. Flat	Water vs. Flat
Perceived bend angle	$\chi^2(3) = 14.59$, $p = 0.002$	$Z = -2.49$, $p = 0.0065$	n.s.	n.s.	n.s.	$Z = -2.81$, $p = 0.0025$	n.s.
Actual bend angle	$F(1.9, 26.5) = 4.65$, $p = 0.020$	$t(14) = -2.72$, $p = 0.008$	n.s.	n.s.	n.s.	$t(14) = -3.11$, $p = 0.004$	n.s.

Table F.2: Statistical comparison of sonification effects during reach forward with the wearable device on awareness, performance, motivation and relaxation. Bonferroni correction was applied to multiple comparisons ($p=0.008$ corresponding to a significance level of $\alpha=0.05$). Non-significant comparisons are marked as n.s.

Measure	Friedman tests	Wave vs. No sound	Water vs. No sound	Flat vs. No sound	Wave vs. Water	Wave vs. Flat	Water vs. Flat
Awareness	$\chi^2(3) = 33.025$, $p < 0.001$	$Z = -3.24$, $p = 0.0005$	$Z = -2.96$, $p = 0.0015$	$Z = -2.40$, $p = 0.008$	$Z = -3.30$, $p = 0.0005$	$Z = -3.20$, $p = 0.0005$	n.s.
Performance	$\chi^2(3) = 32.819$, $p < 0.001$	$Z = -3.23$, $p = 0.0005$	$Z = -3.13$, $p = 0.002$	n.s.	$Z = -3.10$, $p = 0.001$	$Z = -3.21$, $p = 0.0005$	n.s.
Motivation	$\chi^2(3) = 25.935$, $p < 0.001$	$Z = -3.08$, $p = 0.001$	$Z = -2.83$, $p = 0.0025$	n.s.	n.s.	$Z = -3.07$, $p = 0.001$	n.s.
Relaxation	$\chi^2(3) = 18.892$, $p < 0.001$	$Z = -2.54$, $p = 0.0065$	$Z = -2.53$, $p = 0.0065$	n.s.	n.s.	$Z = -2.54$, $p = 0.065$	n.s.

Table F.3: Statistical comparison of sonification effects during physical activity using the Kinect-based device on awareness, performance, motivation and relaxation. Bonferroni correction was applied to multiple comparisons ($p=0.0017$ corresponding to a significance level of $\alpha=0.05$). Non-significant comparisons are marked as n.s.

Measure	Friedman tests	Wave sound vs. active listening	Wave Sound vs. Naturalistic Soundscape	Active listening vs. Naturalistic Soundscape
Awareness	$\chi^2(2) = 11.17, p = 0.004$	n.s.	$Z=-2.81, p=0.0025$	$Z=-2.20, p=0.0014$
Performance	$\chi^2(2) = 4.67, p = 0.097$	n.s.	$Z=-2.25, p=0.012$	n.s.
Motivation	n.s.	n.s.	n.s.	n.s.
Relaxation	n.s.	n.s.	n.s.	n.s.

F.2 Sonification to facilitate transfer from exercise to function

Table F.4: Results from the comparisons of the effects between sound conditions with and without target on awareness, performance, motivation and relaxation. Non-significant comparisons are marked as n.s.

	Measure	Flat	Wave	Water
Target vs. no target	Awareness	n.s.	$Z=-2.04, p=0.041$	n.s.
	Performance	n.s.	$Z=-2.04, p=0.041$	n.s.
	Motivation	$Z=-2.21, p=0.027$	$Z=-2.04, p=0.016$	$Z=-1.98, p=0.047$
	Relaxation	n.s.	n.s.	n.s.

Figure F.5: Results from statistical comparisons between the sound conditions (different amounts of information) using the wearable device and performing movement aimed towards a target. For each type of measure, Friedman's test between the three conditions and planned pairwise comparisons using Wilcoxon (Bonferroni correction $p=0.008$ corresponding to a significance level of $\alpha=0.05$) are presented. Non-significant comparisons are marked as n.s.

Measure	Friedman tests	Wave vs. No sound	Water vs. No sound	Flat vs. No sound	Wave vs. Water	Wave vs. Flat	Water vs. Flat
Awareness	$\chi^2(3) = 34.80, p < 0.001$	$Z=-3.32, p=0.0005$	$Z=-2.96, p=0.0015$	$Z=-2.57, p=0.0065$	$Z=-3.22, p=0.0005$	$Z=-3.22, p=0.0005$	n.s.
Performance	$\chi^2(3) = 33.18, p < 0.001$	$Z=-3.23, p=0.0005$	$Z=-3.13, p=0.001$	n.s.	$Z=-3.10, p=0.001$	$Z=-3.21, p=0.0005$	n.s.
Motivation	$\chi^2(3) = 32.14, p < 0.001$	$Z=-3.22, p=0.0005$	$Z=-3.13, p=0.001$	$Z=-2.39, p=0.008$	$Z=-2.99, p=0.0015$	$Z=-3.20, p=0.0005$	n.s.
Relaxation	$\chi^2(3) = 13.08, p = 0.004$	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.

Appendix G. Part 3 - Study protocol: Investigating sound-space in a situated context

- **Structure of the study: Home study**
- **Duration: 1 week/ participant**
- **Number of participants:**
- **Interviews: 4**

Day 1.

Materials:

- Consent form, information sheet, participant questionnaire
- Video camera, tripod
- Go-with-the-flow kit (phone, wearable, remote)
- Diary

Explain study:

We are running a study to evaluate how you use this device during physical activity sessions and otherwise while doing chores. We will run interviews on the 3rd and last day of the study to evaluate how you feel when using it. My details are on the information sheet and you can contact me at any time during the running of the study to ask any questions.

Did you read the information sheet and consent forms and do you have any questions/ concerns? Can you please read and sign it whenever you are happy.

Questionnaires:

- a. Demographics
- b. Medical history and pain medication.
- c. Self-evaluation (STAI)
- d. Work and social adjustment scale (WSAS)
- e. HADS
- f. Physical activity questionnaire
- g. Pain catastrophising scale
- h. Pain rating scale
- i. Pain NRS
- j.

Ok, let me first explain the device and how you will use it.

- Also explain the video camera and how you want to use it.

Questions for the study:

Questions related with if the use of the device would promote awareness and self-efficacy through sound:

1. Can people using sound design exercise spaces? Are there anchor points or other ways of using sound that can increase confidence and self-efficacy?
2. Can sound be used for self-management to transfer skills such as setting targets for activity and identifying similarities between exercise demands in different exercises?
3. Can this design of sound be extended from exercise to functional activity?
4. To what extent is sound sufficient as a modality to model information about physical activity?

Interview 1:

Step 1: Calibration (no sound)

Step 2: Exploratory stretch:

The person will be told the sounds and asked to speak aloud while stretching about what they are feeling in terms of the stretch and what they can hear (music sounds). Ask pain level after each condition.

Step 3: We will give them information about the sounds and they will repeat the stretch. Step 3 will be repeated twice. Ask pain and anxiety level after each condition.

Interview 2/3:

1. How did you use the device?
 - a. During physical activity?
 - b. During functional activity?
2. How often did you calibrate? Did you notice any patterns?

3. One event that went well, one that didn't, general thoughts - Diary

4. Did it help? In what way?
5. Was it comfortable to wear? Did you have any concerns?
6. What would you change in the app/ add?
7. What would you keep?
8. What would you add?
9. What did you think of the sounds?
10. Show progress

What do you think about that?

Is it what you expected?

11. How can the device be improved?

12. Does the device affect how much you did?

13. Do you still feel motivated to use the device?

14. How did sounds affect your movement (if at all)

- a. Did it help?
- b. Engaging?
- c. Distracting?
- d. Confusing?
- e. Encouraging?
- f. Did the sound make you more/ less aware of the extent of your movement?
- g. Did the sound make you more/ less aware of the smoothness of your movement?
- h. Did the sound make you more/ less aware of the symmetry of your movement?

Create cheat sheet for triggering thoughts – to give.

Progress:

15. Fitbit example (if needed):

The indicator lights illuminate as you hit 20% increments towards your goal. Tap your Flex to see your progress. When you reach your goal, Flex will celebrate by buzzing and flashing its lights.

16. Feedback other than sound

Interview 4: Progress:

What progress do you want to track?

What does that progress look like?

Appendix H. Coded interview samples from study data in Part 1

Figure H.1: Coding sample of interview of participant P1.

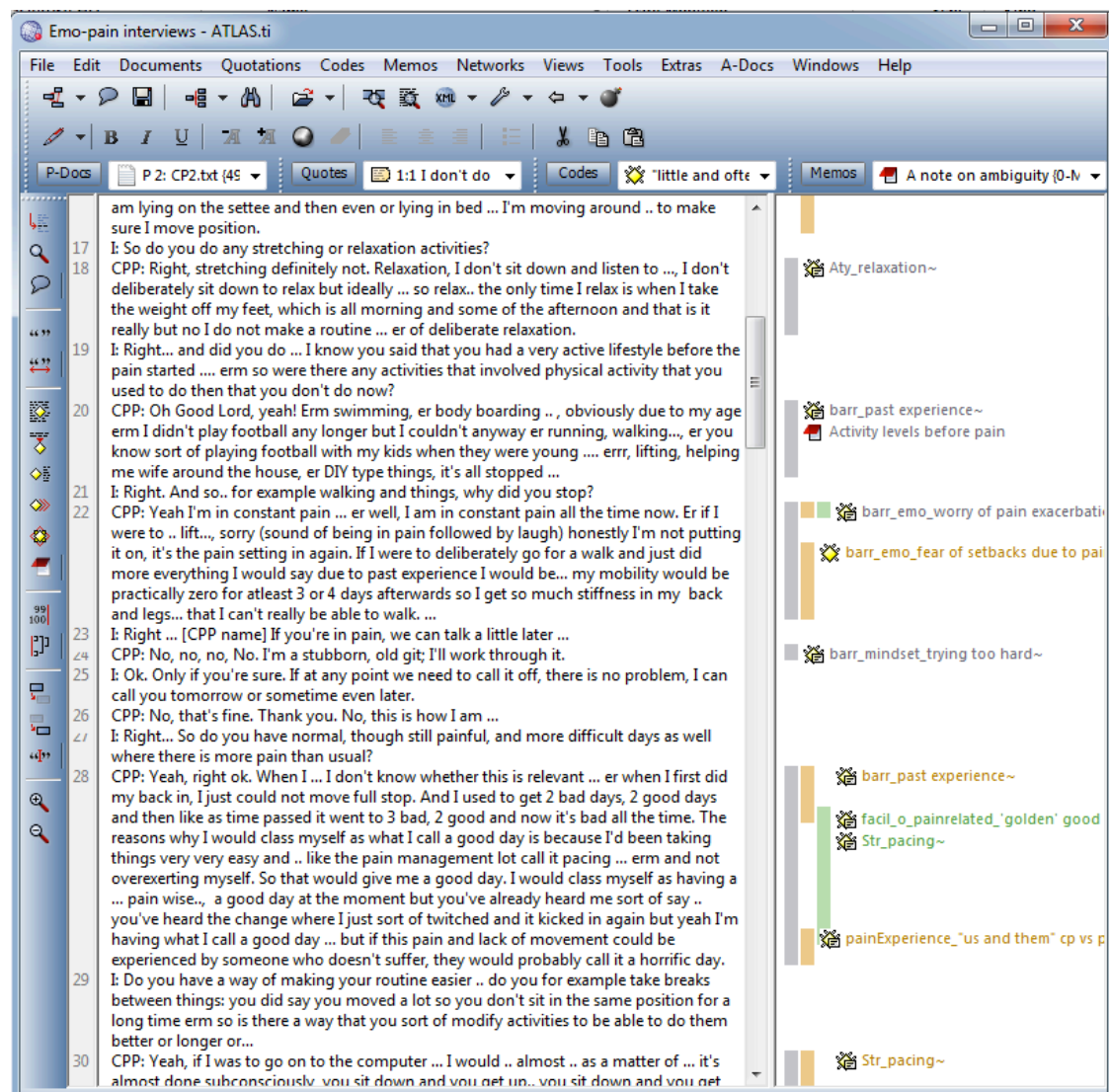


Figure H.2: Coding sample of interview of participant P2.

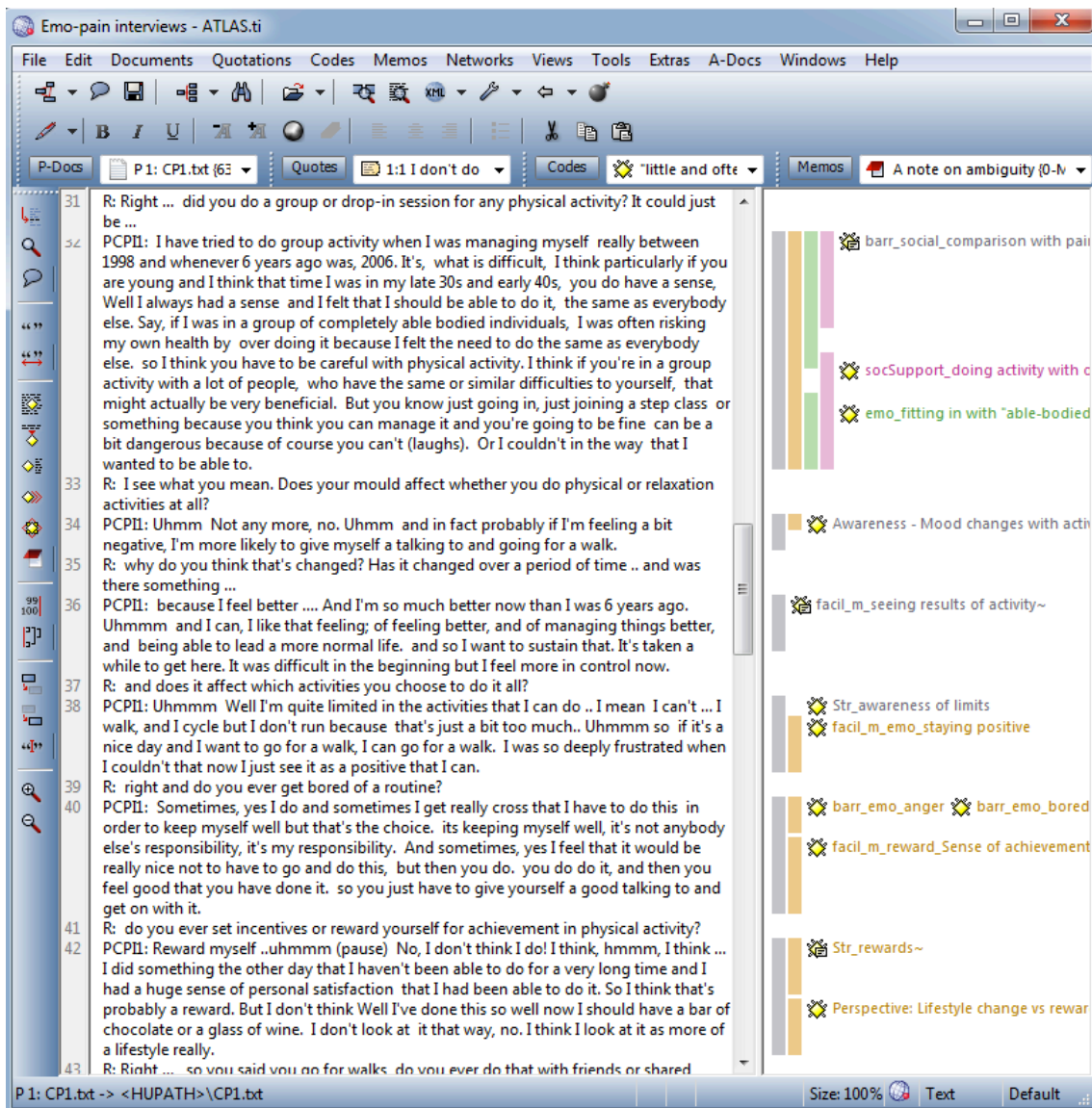


Figure H.3: Memos created for notes on analysis

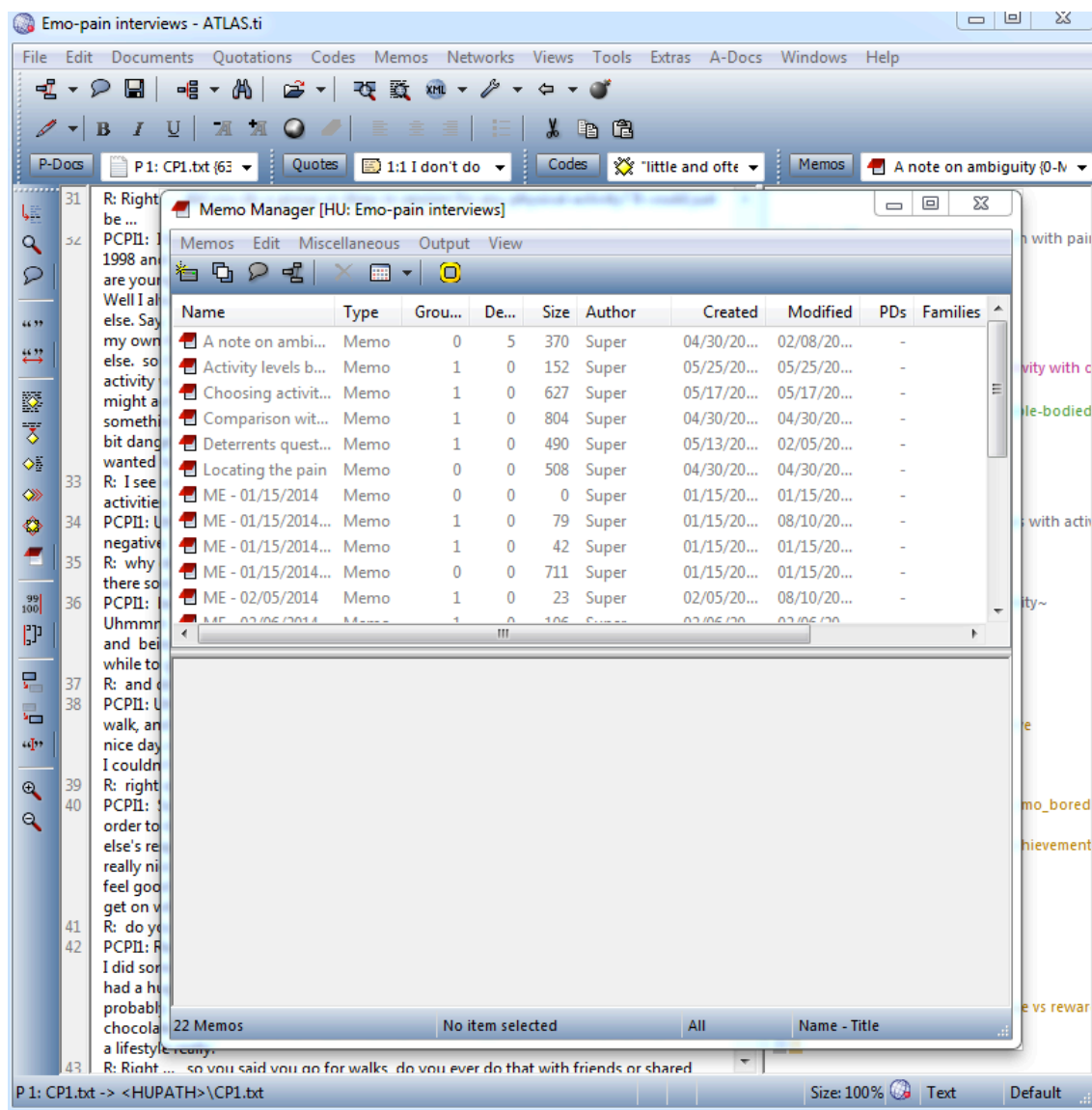


Figure H.4: List of codes for emotional barriers. All codes were colour coded to make integrating them easier.

Code Manager [HU: Emo-pain interviews]		
Codes Edit Miscellaneous Output View		
Name	Families	Created
✖ barr_pain management course_not tailored to individual capability	Barriers	08/02/20...
✖ barr_painBelief_Biomechanical model of pain	Beliefs, WIP	08/06/20...
✖ barr_painrelated_overdoing activity~	Barriers	07/17/20...
✖ barr_painrelated_setbacks/ flare ups	Barriers	07/18/20...
✖ barr_past experience~	Barriers	02/03/20...
✖ barr_phy_age	Barriers	03/20/20...
✖ barr_phy_presence of pain	Barriers	08/06/20...
✖ barr_prac_accessibility		08/05/20...
✖ barr_prac_bad pain days	Barriers	02/09/20...
✖ barr_prac_design of equipment not ergonomic for CP	Barriers	08/06/20...
✖ barr_prac_financial	Barriers	05/13/20...
✖ barr_prac_fitness industry unaware of CP issues	Barriers	03/20/20...
✖ barr_prac_hard to keep routine	Barriers	07/18/20...
✖ barr_prac_healthcaresystem_lack of support	Barriers	03/20/20...
✖ barr_prac_healthsystem_disillusioned by pain management course~	Barriers	08/01/20...
✖ barr_prac_holiday periods and busy times	Barriers	07/18/20...
✖ barr_prac_increased pain_bad weather/cold exacerbates pain	Barriers	02/09/20...
✖ barr_prac_lack of opportunities	Barriers	05/13/20...
✖ barr_prac_lack of time	Barriers	02/09/20...
✖ barr_prac_low motivation_lack of tangible progress in valued goals~	Barriers	01/15/20...
✖ barr_prac_painrelated_lack knowledge of pain/ pain management principles	Barriers	08/07/20...
✖ barr_prac_painrelated_lack of acceptance	Barriers	08/07/20...
✖ barr_prac_painrelated_unpredictable nature of pain~	Barriers	07/17/20...
✖ barr_prac_side effects of medication	Barriers	07/17/20...
✖ barr_prac_tiredness	Barriers	08/13/20...
✖ barr_social_comparison with others	Barriers	03/20/20...
✖ barr_social_comparison with pain-free people~	Barriers	07/31/20...
✖ barr_social_lack of family support	Barriers	03/22/20...
✖ barr_social_lack of healthcare resources	Barriers	03/20/20...
✖ barr_stiffness and muscle tension		08/04/20...
✖ Bct_challenge negative thoughts~	Behaviour change techniques	05/17/20...
✖ bct_graded tasks~	WIP	04/30/20...

Appendix I. Commercialisation

As part of the UCL Advances Enterprise Scholarship, this chapter outlines the potential commercialization opportunities that arose from my PhD course of study. When researching the thesis and running studies, we were acutely aware of the lack of technologies available for real-time support of physical activity in people with CP. CP is a huge healthcare concern. It accounts for 20% of the UK's total health expenditure (Donaldson 2009). 7.8 million people in the UK live with chronic pain and £584 million is spent on prescriptions for pain. 25% of people with chronic pain lose their jobs and 16% feel their chronic pain is so bad that they sometimes want to die (Donaldson 2009). The scale of the problem is such that clinical resources are unable to meet demand and many people do not get the help they need as previously discussed in the thesis. Even people who attend pain management programmes (that last one month) cannot maintain the gains they make in the long-term because of lack of support.

Existing commercially available technology for pain management is in the form of apps aimed at self-monitoring pain levels, mood and motivation for post self-reflection. Technology that addresses real-time support is limited to dedicated exercise sessions in front of a screen (e.g. Valedo: www.valedotherapy.com) and does not support ubiquitous or functional activity. Our studies in the thesis indicated that people often treat exercise as a lower priority than functional tasks. There is a gap in commercially available technology for CP as discussed in the thesis. While fitness and personal information sensor-based wearable technologies have created a revolution amidst the fit population, they are still not being designed for and with an understanding of long-term conditions such as CP and this leaves out a huge section of the population. Using the scholarship provided by UCL advances, we set out to address this gap

We believe there is a need for (and corresponding gap in) healthcare technology provision that can (i) help people to remain physically active by providing real-time feedback tailored to their psychological needs; (ii) make pain management programmes run by the NHS more effective by using low-cost sensing and interactive wearable technology to facilitate understanding of one's capabilities and how to build on them; (iii) help people to extend skills gained during such programmes in long-term self-management of their activity. This gap can be addressed by the *Go-with-the-flow* app informed by an in depth understanding of the psychological needs in physical rehabilitation in CP.

Based on talking with physiotherapists and companies interested in our research, we identified a clear need to design sensing and interactive technology that is developed with expert input from physiotherapists and people with CP. Having created low cost prototypes using just the smartphone (iPhone and Android) or low cost sensors (Arduino-based) and evaluated them with

people with CP and physiotherapists, we believe that there is a tremendous scope for creating impact using such technology.

Commercialising the wearable *Go-with-the-flow* device that provides real-time feedback during activity developed leveraging the research done through my PhD, can provide an accessible, evidence-based, solution to bridge the gap between provision of healthcare and long-term support for people with CP. This commercial potential was borne out after talking with other entrepreneurs and experts at various events such as the Social Innovators Challenge, healthcare providers and my supervisor.

Our initial goal for the scholarship was to extend the Go-with-the-flow device to be used in the home context to develop strategies and the device further for use in the home. In Chapter 11 that customisation has of the device has been presented.

Business and Entrepreneurial Training

I expanded my business knowledge by attending courses and boot camps offered by UCL Advances such as the three day Enterprise Bootcamp that covered topics about business principles in general, making business plans and also entrepreneurial pursuits. I also attended other app entrepreneur courses run by freelancers and industry. I approached people in UCL Advances and UCL Business to discuss the Go-with-the-flow app and possible models for commercialising it. These courses, lectures, and advice on approaching commercialisation of the wearable app was useful to me to develop an understanding of what an app startup model would look like.

However, so far, before getting funding from UCL Enterprises, our app was a research tool and had not been used by participants on their own. While many participants had expressed a desire to use the app in the home, it had not been possible because we had designed it as a research tool not an end user device. So the first step was to redesign the app, presented in Chapter 11.

After redesigning the app and left it with people with CP for 7-14 days to use in the home. People found the app easy to use and used it to develop strategies for integrating exercise and functional activity in the home as discussed in Chapter 11.

Market research and revenue model

Our aim from commercialising this research is to create a social venture with the prime objective of solving the problem of motivating and supporting physical activity in people with CP and providing the social benefits that arise from this solution. While social ventures may generate profits, that is not our focus. Rather profits could be used to sustain the social benefit provided by the app. Hence, generating revenue is an important concern.

Gartner (www.gartner.com/newsroom/id/2153215) predicted that of the 309.6 billion app downloads by 2016, 93 percent will be free i.e. only 7% of app downloads will be paid

for. Therefore, to effectively compete by developing an app in this market we need to carefully consider the options. 5 main revenue generating models exist in the mobile app business: (i) pay to download where users pay for each download but an app cannot be resold to the same subscriber, (ii) in-app advertising where apps can be downloaded for free but app owners are paid by advertisers if users click on the in-app advertisements, (iii) in-app purchasing where a basic version of the app is provided for free but additional levels or features can be purchased, (iv) freemium where apps are free but generate revenue by selling related products or providing services, and (v) subscription where the user has to pay for continued usage of the app.

We also reviewed prices of apps for CP on the iPhone and android platforms, which are presented in the tables G.1 and G.2 below to plan our strategy (presented after the table).

Table G.1 CP-related app prices for Android phones

App Name	Description	Price
My Pain Diary	Makes it easy to track your chronic pain & report to your doctor	2.98
Chronic Pain Manager	Tracks your pain levels, pain location and medications with Chronic Pain Manager	Free
Pain Diary & Forum - Catch my pain	Track and manage your pain: migiraine, fibromyalgia, lupus, arthritis, back	Free (In-app purchases)
Chronic Pain Diary	Designed to allow chronic pain patients to record daily pain-scores and relevant clinical details	Free
Manage my pain Lite	The leading pain management app to record, track, analyze & share your pain	Free (In-app purchases)
Fibromyalgia	About Fibromyalgia, a chronic pain syndrome characterized by widespread pain	Free
Health Log	A quick, easy and flexible way to track your health	Free (In-app purchases)
MyFibroTeam Mobile	MyFibroTeam: the social network for people living with fibromyalgia	Free
Fibromyalgia Information	This app provides complete information about fibromyalgia diseases	Free
Arthritis Symptoms + Treatment	Arthritis Symptoms, Arthritis treatment for Rheumatoid Arthritis and other types	Free (In-app purchases)
Fibromyalgia Magazine	Fibromyalgia Magazine, providing support for the worldwide fibromyalgia family	Free (In-app purchases)
Arthritis Today	provides the most current and trustworthy advice on treatments	Free (In-app purchases)
Get Pain Relief! Chronic Pain	Get Pain Relief! Less Chronic Pain for Hypnosis	2.77
Manage my pain Pro	The leading pain management app to record, track, analyze & share your pain	2.99
FibroMapp	Pain management app designed specifically for Fibromyalgia and CFS/ME	2.39

Table G.2 CP-related app prices for iPhones

App Name	Description	Price
Chronic Pain Tracker Lite	Record your pain summary with 19 unique health categories. Review a summary report with your doctor in the app, or export a PDF for printing/emailing.	Free
My Pain Diary HD: Chronic Pain & Symptom Tracker	Track your chronic pain, symptoms, triggers and more to create detailed report your doctor will love.	3.99

App Name	Description	Price
Pain Relief Hypnosis Free - Management & Treatment of Arthritis, Fibromyalgia & Other chronic pains	Learn to reduce pain and relax after listening daily for just 1-3 weeks. Retrain your body to allow for comfort through subconscious thoughts. Prevent chronic pain from interfering with your work, sleep and life.	Free (In-App Purchases)
Fibromyalgia & Chronic Pain Life Magazine	A quarterly publication offering the latest news and information about Fibromyalgia and Chronic pain. A universal life management diary tracker to journal, track, analyze, improve & share chronic pain symptoms, such as pain and sleep, my work life, food, weight & wellness.	Free (In-App Purchases)
TracknShare Back Pain - Causes and Relief of Any Chronic Ache or Pains from Damage or Strain Pain Diary & Community - CatchMyPain	Learn all about the cause and possible treatments of acute and chronic back pain	3.99
Pain Scale - your digital log for chronic pain	Keep a medical health record, track your pain, diagnosis and symptoms and share it with your doctor iPainScale is your digital pain scale app. Individual pain estimations will be saved automatically along with date, time and optional note. Create a PDF report with your entries and save them or email them to your healthcare professional.	Free (In-App Purchases)
The Simplyhealth Back care App Get Pain Relief! Chronic Pain	Offers information and advice to help you manage and prevent back pain. There are graphics and videos of exercises for you to follow and you can input the area and strength of your pain to find those suitable for you.	Free
Chronic Pain Tracker Pain Diary & Community - CatchMyPain PRO Pain Relief Hypnosis PRO - Management & Treatment of Arthritis, Fibromyalgia & Other chronic pains	App in German language only currently Take the guess work out of pain management with Chronic Pain Tracker. Record your pain history with 19 unique health categories. Review your summary report with your doctor in the app, or export a PDF for printing/emailing.	2.99
Back Pain Exercise - Learn how to treat lower back pain at home	Learn all about the cause and possible treatments of acute and chronic back pain	7.99
Chronic Fatigue Syndrome Diary	Learn to reduce pain and relax after listening daily for just 1-3 weeks. Retrain your body to allow for comfort through subconscious thoughts. Prevent chronic pain from interfering with your work, sleep and life.	2.99
Pain Logger Lite Edition	Get natural back pain relief with these tips. Tips for relieving back pain naturally. You can learn from the videos CFS diary makes it easy to perform tasks like tracking your treatment progress, graphing your patterns, emailing reports, including graphical attachments to your doctor and advisors. Use triggers like, day of the month and week, weather patterns, diet, sleep patterns, to predict and manage your CFS. Pain Logger Lite Edition helps you track (and remember) your pain intensity levels over time. Pain Logger Lite Edition helps you definitely find your pain intensity level by tracking your pain levels over time.	2.49
		0.79
		3.99
		Free

App Name	Description	Price
TracknShare Lite	A universal life management diary tracker to journal, track, analyze, improve & share chronic pain symptoms, such as pain and sleep, my work life, food, weight & wellness.	Free

As seen above, iPhone apps are more likely to have a pay per download model. Android apps are more likely have in-app purchases. We were advised by people at UCL Advances as well to go for an iPhone model if we wanted to go for the pay per download model. While the current app is developed on Android, we can invest in a developer to develop the app for the iPhone market if this helps to bring the device to market. Looking at the variable cost of apps on the market and considering we can offer real value and something that is not currently available on the app store, we will consider a price of £3.99 for the initial app. We will do further market research before finalising this price.

Our plan is not just to market the app but also individual movement sensors that can be integrated with the app and also accessories such as remotes and wearable options. We have not yet investigated the cost model for these accessories in detail but some of the end-user sensing devices were checked for pricing. Hocoma Valedo (www.valedotherapy.com) for back pain. Is priced at £259 currently. Others (ViMove from Dorsavi – www.dorsavi.com/vimove) are not available to end-users as they sell directly to doctors and physiotherapists. Sensing devices such as Lumo-lift (www.lumobodytech.com/lumo-lift) are priced at £59.99 for one sensor. We need to cost our what our sensors will cost when developed commercially but prototyping each sensor costs us approximately £46.29.

We want to approach the commercialisation in three phases:

Phase 1: Sale of app – pay per download

- Can be downloaded and used by people with CP, or anyone else (such as wheelchair users, elderly, injured athletes)
- Can be used in conjunction with healthcare provider to understand/ explore body
- Can be used to do exercise, functional activity in the home and outside the house.
- Can be used as a posture and movement tracker.
- Can be used for long-term management of condition and to track progress.
- Can be used to provide awareness of avoidance strategies
- New sonifications, if with different information strategies, will be priced at £0.79 per sonification.
- Pain level tracking

*If users agree to share movement data for research purposes (no personal data), they can get a free version of the app.

Phase 2 – pay per unit.

- Sale of app and IMU units, breathing sensors, more complex movements, enhancing tracking avoidance strategies

Phase 3 – pay per unit.

- Muscle activity

Channels to market

We consider that we will be using the following channels to market the app:

- CP groups – physical and social media
- Pain websites and forums (e.g., Paintoolkit)
- NHS pain programmes, drop-in exercise groups
- Physiotherapist recommendations.
- Collaborations with other products

Commercialising the app: planning of a two phase approach

Phase 1

Develop a smartphone app with accessories

- Smartphone app with bluetooth remote (easy to access, can be used in clinic or home).
- Iron-on smartphone pocket (lightweight, customisable)

Target audience

- At home to self-manage for people with CP
- In clinic/ hospital/ gym with hospital or trainer
 - To help calibrate and explore
- Wider audience - can be used with the same design not just for CP but shown interest by the elderly and people with injuries or in wheelchairs.
- People can download app to use it.

Phase 2

- Extend the wearability of the device so IMUs can be placed in different pockets. We can even use tape for a more advanced IMU like current commercial sensors placed on the skin.
- Phone can be used as the controller
- Sound will come from the IMU units.
- This version needs development and testing
- Phase 2: Sale of app and IMU units, breathing sensors, more complex movements, enhancing tracking avoidance strategies

Phase 3

- Muscle activity and pain level tracking

Future plans

As our app is fully developed, we plan to launch it in the UCL App Store for testing to gauge the response of users in an exploratory way and continue with market research. We plan to release a stable version of the app within the next three months and we will start work on phase 2 of the project while supporting users in phase 1.

With the increasing focus on mobility, we expect that the app will be useful to people with CP but also to other conditions such as sports injuries, wheelchair users, the elderly or for use in practising controlled movements.